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Chronic Diseases and Injuries in Canada
Public Health Agency of Canada
785 Carling Avenue
Address Locator 6806B
Ottawa, Ontario K1A 0K9

Fax: 613-941-2057
Email: cdic-mcbc@phac-aspc.gc.ca

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Editorial

Bicycle injuries and injury prevention

I. B. Pless, CM, MD, FRCPC

In 1989, long before this journal added injuries to its title, it published two papers on childhood injuries and I was asked to write an editorial for this occasion. I chose the title "Challenges for Injury Prevention: Two Neglected Aspects"[1] because I thought the papers neglected to mention the inadequacy of injury statistics (at the time there were no emergency department data) and also failed to emphasize the public health importance of childhood injuries. It is instructive, therefore, to compare this issue's offerings with how matters stood nearly 25 years ago and see what progress we've made.

Papers in this and the previous issue of this journal discuss bicycle safety in general and helmet use in particular. Although this is a somewhat narrow focus, it serves as one indicator of how the field has evolved and what remains to be done to improve both the science and policy in this domain.

The literature (and media) is still riddled with anti-bike helmet and anti-helmet legislation papers. The arguments range from "helmets are ineffective when hit by a car" (this is only partly true because at least one paper shows that even in crashes they provide some protection[2]) to "they send the wrong signal that bicycling is dangerous" (this is false; bicycling can be dangerous).[3] Moreover, there is no strong evidence that wearing a helmet makes cycling more dangerous, as some suggest. For example, one intriguing report[4] that later work discredited[5,6] proposed that helmets encourage drivers to ride closer to bicyclists. Many of the anti-legislation papers rely heavily on one Australian study[7] for evidence that legislation decreases ridership (but overlook many other studies, for example, a long-term study of bicycle-related head injuries conducted by Olivier et al.[8] that convincingly demonstrate no significant post-legislation decline). The anti-legislators also argue that less cycling leads to more obesity and other ill effects on our health but no papers provide good evidence in support of this argument.

Neither the original Australian report[7] nor any others have told us how long the decline in riding (if any) persisted following legislation. Nor has anyone provided physiological data to support the assertion that any such decline actually decreases fitness or increases obesity rates.[9] Even if true (which I doubt because most bicyclists do not ride long enough or fast enough to burn many calories), this does not mean that helmet legislation is not in the interest of public health. The cost—economical, physical and psychological—of a single serious head injury is significant. In this light, the importance of preventive action, including legislation requiring helmet use, becomes obvious. I am not suggesting that the problem of obesity among Canadian children is trivial; it is not. But in the context of the helmet legislation debate, the figures simply do not add up.

A recent Canadian judgment awarded a family $3 million for a child who had been severely injured when skiing.[10] And, during just one follow-up year, the medical costs of patients hospitalized with a traumatic brain injury (TBI) in Ontario were $120.7 million.[11] Miller,[12,13] a leading health economist in the United States, and his associates consistently show the enormous cost benefit of wearing a helmet. One such study estimated the total cost of TBI, including medical care, work loss and change in quality of life, at $206 billion (USD) for 1.3 million cases.[12] For severe (Abbreviated Injury Score [AIS] 4–6) head injuries in all age groups, the average cost per patient was over $1 million (USD), and for the very severe (AIS 6), $3.3 million (USD); even for child cyclists with any TBI (severe and less severe), the average cost was $62 000 (USD).[13]

And these are just the dollar costs. The emotional cost to child and family are also staggering. In contrast, the cost of obesity as a direct consequence of reduced bicycling—the context in which this issue is being debated—is not known, but it is not likely to approach the numbers given by the head injury studies. To arrive at a figure that is remotely accurate, we would need to know how many children stopped cycling because of helmet laws (the data so far are wholly inconsistent); how many became obese as a direct consequence of not cycling; and how many of these developed type 2 diabetes or heart disease. Then we would need to estimate the dollar costs of treating these illnesses. To the best of my knowledge, no one has published any such estimates.

Nor it is just the serious head injuries that are important to public health. My experience of being "doored" (see photo) convinces me that, had I not been wearing a helmet, my head injury would have been far more serious. Dooring, along with other fairly common events such as falls as a result of potholes or collisions with unwary pedestrians, fully convinces me that helmets are essential even when car crashes are set aside. With this in mind, let's examine what the reports in the previous and current issues of *Chronic Diseases and Injuries in Canada* add to the debate.

Author reference:
McGill University, Montréal, Quebec, Canada

Lindsay and Brussoni[14] discuss pediatric injuries related to all non-motorized wheeled activities, that is, scooters, skateboards and in-line skates as well as bicycles. They use data from the Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP)[15] to generate a portrait of the way children can get injured when using these types of "wheels." Most were injured while cycling, most were boys, and most injuries were the result of falls. So far the findings are not remarkable. However, almost 10% had a head injury, and these were especially common among cyclists. Of note, the authors found that "patients ... in jurisdictions where helmet use is mandated had 2.12 greater odds of helmet use and 0.86 lesser odds of head injury compared with those without helmet laws."[14p74] I agree with their conclusion that the small number of patients who used helmets or other protective gear points to an area that needs intervention.[14] Clearly, that intervention must include efforts to persuade provinces without helmet legislation to reconsider this decision in much the same way as all provinces now view seatbelts.

The study by Romanow et al.[16] from the previous issue of this journal is a step up the evidence ladder because it employs a case control design. The authors examined the effect of bicycle helmet fit and position on head and facial injury risk. Not surprisingly, they found that poor fit or poor positioning increased the odds of a head injury by as much as six times. Although at one level this finding simply affirms the obvious, it is important because poor fit and poor wearing undoubtedly confound the results of most earlier studies of helmet effectiveness. Unless fit was taken into account, these studies will have reported large underestimates of effectiveness. It is much like trying to examine seat belt effectiveness without taking into consideration whether belts were properly fitted or secured.

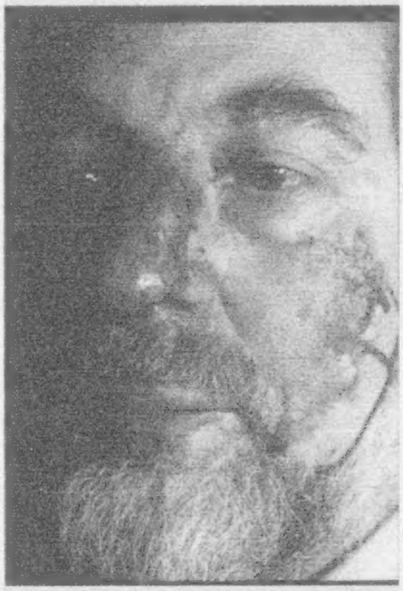
Finally, we have a paper by Parkin et al.,[17] also from the previous issue, about parental attitudes towards and beliefs about helmet use. Its strength is that it compares provinces with and without helmet legislation. Here, too, the findings seem predictable, with parents in provinces with helmet legislation more supportive of such legislation and of enforcement than those in non-legislation provinces. Perhaps surprising, however, is that all other attitudes and beliefs—concern about injury, belief in the effectiveness of helmets, rules about children always wearing a helmet and, most noteworthy, the belief that legislation decreases the amount of time their child spends cycling—are similar to those in "non-legislation" provinces.

It is reasonable to ask which comes first: parents with sensible bike safety attitudes or legislation that helps mould those attitudes? There are no data to help us answer this important question. It is often stated that legislation cannot be enacted until a certain level of public support is reached. What the magical threshold level is, or where studies supporting this view come from, is a mystery. Clearly it is politically much easier for a legislator to promote laws for which there is broad public support than the reverse. But there are many examples of enlightened legislation introduced with little such support. It seems likely that if public health authorities deem an issue serious enough to warrant legislation, eventually attitudes and beliefs will shift in that direction. Conversely, parents may ask how important it could be for their children to be helmeted if their province does not require that they do so.

Helmet law wars aside, how much has the larger bicycle safety picture changed in the last 25 years? Some statistics are encouraging. Although it remains uncertain where the credit belongs, bicycle injuries in Canada have greatly diminished over this period.[18] Canadian Institute for Health Information (CIHI) data show that although "the annual number of cycling injury hospitalizations remained relatively stable between 2001–2002 and 2009–2010, the number of cycling-related head injuries decreased from 907 to 665."[18p1] The report also notes that 78% of the admissions with severe head injury were not wearing a helmet at the time of the injury.[18] However, helmets may have little effect on bicycling mortality. The Vehicular Cyclist[19] cites Transport Canada data from 1975 to 2003 which it interprets as showing "no effect of increased helmet use among cyclists ... [on] prevailing fatality trends." However, it is evident from the data that helmet use increased and pedestrian and bicyclist deaths decreased over this time period by 42% and 39%, respectively. The article chooses to attribute these declines to "general safety campaigns, such as those involving roadside breath-testing of motorists and speed surveillance using radar equipment,"[19p1] implying that helmet use played no role. But these data don't mean helmets are ineffective; they may simply illustrate that a helmet is a poor match for a few thousand pounds of steel and that legislation without enforcement is meaningless.

With respect to the challenges I issued in 1989, have we progressed much or little? To be sure, we have better injury morbidity data thanks to CHIRPP and the National Ambulatory Care Reporting System (NACRS), but we remain almost as unresponsive to the findings as we were in 1989. Although several organizations have emerged to address the problem—the latest being Parachute (http://parachutecanada.org), an amalgam of Safe Kids Canada, SMARTRISK and Safe Communities—and some provinces are taking important preventive initiatives,[20,21] injury prevention still sees far too little public health action in Canada.

FIGURE 1
The author, after being "doored" while cycling slowly on a quiet street



My 1989 editorial concluded: "Even if we had the best statistics, what is still lacking is a concerted effort to address this issue in the same aggressive manner as we have pursued the eradication of communicable diseases. For the most part the technology and much of the [knowledge] is there; what remains is for us to … assemble the Canadian equivalent of Injury in America. With a few more resources and a solid commitment, Canada could be among the front-runners in the race to conquer injuries. If we choose otherwise, to mix the metaphor … we will instead languish in the minor leagues for another decade—or more."[1p2] I would only change what I wrote slightly, substituting the word quarter-century for the word decade.

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Injuries and helmet use related to non-motorized wheeled activities among pediatric patients

H. Lindsay, MD (1, 2); M. Brussoni, PhD (2, 3, 4, 5, 6)

This article has been peer reviewed.

Abstract

Introduction: Patients presenting to emergency departments (ED) for injuries resulting from recreational activities represent a unique source of information on important directions for injury prevention efforts. We describe the epidemiology of non-motorized wheeled activity-related injury in pediatric patients presenting to Canadian EDs as well as patients' helmet use.

Methods: Data for the years 2004 to 2009 were abstracted from the Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP), a national ED injury surveillance program in fifteen hospitals.

Results: Most of the 28 618 children aged 1 to 16 years injured during non-motorized wheeled activities were injured while cycling, followed by skateboarding. Most injuries occurred among boys. Children injured on scooters tended to be younger whereas skateboarders were the oldest. On average, the number of all injuries decreased by 6% over the time period. Falls were the most common mechanism of injury; 8.3% of patients had head injuries, which were seen more often among cyclists than other wheeled-activity users. Helmet use was greatest among cyclists (62.2%) and lowest among skateboarders (32.9%). Injured patients presenting to EDs in jurisdictions with legislation mandating helmet use had 2.12 greater odds of helmet use and 0.86 lesser odds of head injury compared with those presenting in jurisdictions without helmet laws.

Conclusion: These results provide further evidence that legislation mandating helmet use may be an effective way of reducing injury among all wheeled-activity users. The small number of patients who presented with helmet use and protective gear (59.4% overall) suggests that this remains an area for intervention.

Keywords: child, bicycling, in-line skating, skateboarding, scooters, helmet use

Introduction

Non-motorized wheeled activities result in significant injury-related morbidity and mortality in children.[1,2] According to the National Trauma Registry, 27 589 people were hospitalized in Canada due to injuries secondary to wheeled activities between 2004 and 2009, and 22 023 of these hospitalizations were among cyclists.[2] However, these numbers represent only admissions to hospital, and fail to account for the full impact to the health care system, as many injuries are treated in emergency departments (ED) or on an outpatient basis (i.e. fractures and minor head injuries).

Several studies comparing injury patterns in different wheeled activities have demonstrated differences based on age distribution.[3-5] Previous studies have suggested that, while cyclists suffer a greater number of fractures due to the popularity of cycling, the proportion of fractures is greater with the use of other non-motorized wheeled devices.[6] Fracture rates among injured pediatric cyclists presenting to Canadian EDs have ranged from 26.3% to 28.9%,[7,8] whereas a Norwegian study that looked at small-wheeled devices reported that 69% of in-line skaters, 48% of skateboarders and 49% of scooter users presented with fractures.[3] Similarly, Canadian data demonstrated fracture rates of 36.6% to 48.1% among users of small-wheeled devices.[8]

Previous studies have used ED injury surveillance data from the Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP) to outline injury patterns in Canada among cyclists[7] and in-line skaters.[9] Hospitalization data from a 2002 Canadian study suggested that there have been decreases in severe injuries from cycling since the widespread implementation of helmet laws.[10] However, with the exception of one 2009 study that used Alberta Children's Hospital CHIRPP data to examine injuries from wheeled shoes and compare injury patterns and helmet use across other wheeled activities, few studies have compared injury patterns or helmet use in different wheeled activities.[6] Thakore et al.[6] found injuries to the head and face in 15% to 22% of users regardless of the type of wheeled activity; they also

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Author references:

1. Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada
2. School of Population and Public Health, University of British Columbia, Vancouver, British Columbia, Canada
3. Department of Pediatrics, University of British Columbia, Vancouver, British Columbia, Canada
4. British Columbia Injury Research & Prevention Unit, Vancouver, British Columbia, Canada
5. Child & Family Research Institute, Vancouver, British Columbia, Canada
6. British Columbia Children's Hospital, Vancouver, British Columbia, Canada

Correspondence: Mariana Brussoni, F511–4480 Oak Street, Vancouver, BC V6H 3V4; Tel.: 604-875-3712; Fax: 604-875-3569; Email: mbrussoni@cw.bc.ca

found that fractures were, in fact, more common among non-cyclists in Alberta.

The aim of our current study is to analyze CHIRPP ED surveillance data to describe the epidemiology of injury related to non-motorized wheeled activity as well as helmet use in pediatric patients presenting to EDs, and to determine if helmet use varies based on regional legislation. Examining Canada-wide ED data and outlining the types of injuries with which users of these devices are presenting can help target injury prevention strategies. Administrative data sets, such as discharge abstract data, capture only a fraction of injury cases because the majority of injured children, particularly those with less severe injuries, are not admitted to hospital. Further, these data sets neither describe injury events nor record use of safety equipment, while CHIRPP ED surveillance data permit such levels of analyses.

Methods

Data on patients with injuries caused by all wheeled, non-motorized devices were abstracted from CHIRPP for the years 2004 to 2009. CHIRPP is a national ED surveillance program that registers injury cases from 11 pediatric and 4 general Canadian hospital EDs in the following municipalities: Vancouver (B.C.), Calgary (Alta.), Edmonton (Alta.), Winnipeg (Man.), London (Ont.), Kingston (2; Ont.), Ottawa (Ont.), Montréal (2; Que.), Québec (Que), Toronto (Ont.), Halifax (N.S.), St. John's (N.L.) and Arctic Bay (Nvt.).[11] Any patient or caregiver presenting with an injury is asked to voluntarily complete a form about the injury event. If the patient or their proxy is unable to complete the form, a staff member fills in the report based on interviews or from the patient's chart. Questions on the form describe the circumstances surrounding the injury, including the factors causing or contributing to the injury and the time and place of the injury event. Medical diagnostic information is coded by a local CHIRPP coordinator.[11] The collated injury reporting forms are sent to the national CHIRPP centre at the Public Health Agency of Canada, where they are coded by a trained data support officer.

Our analyses included pediatric patients presenting to any CHIRPP hospital. As a majority of the CHIRPP hospitals are pediatric centres, and many of them only treat patients aged up to 17 years, we included only patients aged between 1 and 16 years (12 to 203 months), inclusive. A number of variables in CHIRPP ensure complete capture of all cases of non-motorized wheeled activities. These include "activity at the time of injury" (Context), "factor codes" and "narrative fields" (Injury Event Description and Product). Cases were included if (1) the activity at the time of injury was coded as bicycling (including unicycles and tricycles), skateboarding, in-line skating/rollerblading or using a scooter; or (2) any of the six CHIRPP factor code fields contained a value for any one of the four non-motorized wheeled devices (bicycle, skateboard, scooter or in-line skates/roller blades); or (3) the narrative fields contained any of a number of text strings (French and English) related to the four activities/devices. Different types of each device were included; unicycles and tricycles were counted as bicycles and no distinction was made between roller skates and in-line skates. After receiving the coded data from the national CHIRPP centre, each narrative text string in the data set was examined. If the narrative text indicated that the injury did not take place during use of a wheeled device or that the device in question was either motorized or a stroller, the record was excluded. Use of helmet was defined by the patient or caregiver checking "helmet" on the CHIRPP form that asks if any safety equipment was being worn when the injury occurred. Protective gear was considered as being used if any of the others options were checked on the same question ("sports padding," "mouthguard," etc). Study methods were approved by the Children's and Women's Hospital of British Columbia Research Ethics Board.

Of the eight provinces represented in CHIRPP, five had jurisdictional legislation mandating helmet use during the years covered in the analysis (either provincial-wide legislation or municipal by-laws that encompass the location of the CHIRPP hospital, for example, St. John's in Newfoundland). All enactments of bicycle helmet legislation took place prior to 2004, although Nova Scotia expanded their helmet laws to include all wheeled activities in 2007.[12] Two provinces, British Columbia and Nova Scotia, mandated use at all ages, while use in Alberta and Ontario was limited to those aged under 18 years, and in St. John's (N.L.) to children under 12 years.

Comparisons were made between the four types of wheeled activities by median age and proportion of sex. Frequencies of injury patterns (as defined by the CHIRPP data set and indicated as present by the treating physician) were compared across activity type, including "fractures," "dislocations" and "head injury." Last, frequencies of helmet use and protective gear were compared across activity type. Data management and analyses were performed using Microsoft Excel (Microsoft Corp, 2010) and SPSS version 20.0 (IBM Corp, 2011). Odds ratios were used to demonstrate significant differences in frequencies, and were calculated by using binary logistic regression adjusting for age, sex and non-motorized wheeled activity, with 95% confidence intervals (CIs) calculated. Generalized Poisson regression was used for time trends to quantify the relationship between year and the number of occurring injuries. To address the overdispersion issue in the count data, we used Pearson chi-square with 95% CI to estimate the scale parameter and obtain more conservative variance estimates and significance levels.[13] β exponential estimates, which tell the relative change in the number of injuries by year, are derived from this regression model. The regression assumes that the denominator (number of people at risk of injury) did not alter over time.

Results

Age and sex demographics

From 2004 to 2009, a total of 28 618 injury patient records met the inclusion criteria, representing 28 618 patients with 35 184 injuries from non-motorized wheeled activities. Patients with cycling-related injuries accounted for 72.8% (20 838/28 618); skateboarding, 17.1% (4892/28 618); scooter-related events, 6.7% (1904/28 618); and in-line skating, 3.1% (891/28 618).

Table 1 shows the sex and age distribution of injuries by the various non-motorized wheeled activities. Most injuries occurred among boys (74.1%). All activities had a greater proportion of boys than of girls, with skateboarding having the largest male to female ratio (8.2), and scooter usage the smallest (1.4). Most children presenting with injuries from non-motorized wheeled activities were between 9 and 12 years old (37.2%), but age distribution varied significantly by sport. Children presenting with scooter injuries were younger, with a median age of 9.4 years; cyclists were slightly older, with a median age of 10.9 years, in-line skaters had a median age of 11.7 years, and skateboarders tended to be the oldest, at a median of 13.3 years.

Time trends in injuries caused while doing a non-motorized wheeled activity

All non-motorized wheeled activities peaked in injury presentation during the summer months, with between 40% and 50% of presentations occurring in the July to September time period across all 6 years. Overall, the number of all-injury presentations as a result of non-motorized wheeled activities decreased significantly between 2004 and 2009 (Figure 1), on average by 6.0% annually (ExpB = 0.94; 95% CI: 0.92–0.96). All types of injury from non-motorized wheeled activities decreased significantly over the years, except injuries among scooter users (ExpB = 1.00; 95% CI: 0.97–1.03). The number of cyclists presenting with injuries decreased on average about 5.1% (ExpB = 0.95; 95% CI: 0.93–0.97), of skateboarders by 9.0% (skateboarders: ExpB = 0.91; 95% CI: 0.86–0.96) and of in-line skaters by about 21.5% (ExpB = 0.79; 95% CI: 0.69–0.90) every year.

Injury patterns from non-motorized wheeled activities

Mechanisms of injury from non-motorized wheeled activities were similar across activities, with falls the most common (82%–91%; data not shown). Collisions and motor vehicle collisions (MVCs) were the two other mechanisms that contributed most to injury. Cyclists presented with MVC as a mechanism of injury 5.9% of the time, while MVCs made up between 1.7% and 4.9% of injury presentations across other activities.

The most common types of injuries seen overall were superficial injuries and fractures, followed by musculoskeletal injuries such as sprains (Table 2). In-line skaters had the greatest proportion of fractures at 46.1%. Severe injuries, particularly those classified as injuries to internal organs or neurovascular injuries or multiple, were most numerous among cyclists. Head injuries accounted for over 8.3% of injuries overall, and were most likely to be among cyclists. Skateboarders had the highest proportion of musculoskeletal injuries such as sprains, and children using scooters had the highest proportion of dental injuries.

The most common type of fracture was of the elbow and forearm across all activities, followed by wrist and hand fractures (Table 3). Skateboarding had the highest count and proportion of ankle and foot fractures.

Helmet use and protective gear

Among children presenting with injury from non-motorized wheeled activities, 55.3% reported using a helmet (excluding missing data; data not shown). The proportion of records by sex, presence of head injury, and admission where helmet

TABLE 1
Sex and age distribution by type of non-motorized wheeled activity, ages 1–16 years, 2004–2009

Sex[a], age (years)[b]	Bicycle		Skateboard		Scooter		In-line skates		Total	
	n	%	n	%	n	%	n	%	n	%
Male										
1–4	1269	6.1	61	1.2	139	7.3	9	1.0	1478	5.2
5–8	3375	16.2	289	5.8	368	19.3	86	9.7	4118	14.4
9–12	5206	25.0	1503	30.2	466	24.5	253	28.4	7428	26.0
13–16	5276	25.3	2587	51.9	136	7.1	182	20.4	8181	28.6
Subtotal	15 126	72.6	4440	89.1	1109	58.2	530	59.5	21 205	74.1
Female										
1–4	637	3.1	9	0.2	61	3.2	5	0.6	712	2.5
5–8	1847	8.9	71	1.4	272	14.3	64	7.2	2254	7.9
9–12	2341	11.2	258	5.2	405	21.3	221	24.8	3225	11.3
13–16	887	4.3	204	4.1	57	3.0	71	8.0	1219	4.3
Subtotal	5712	27.4	542	10.9	795	41.8	361	40.5	7410	25.9
Total	20 838[c]	100.0	4982[c]	100.0	1904	100.0	891	100.0	28 615[c]	100.0

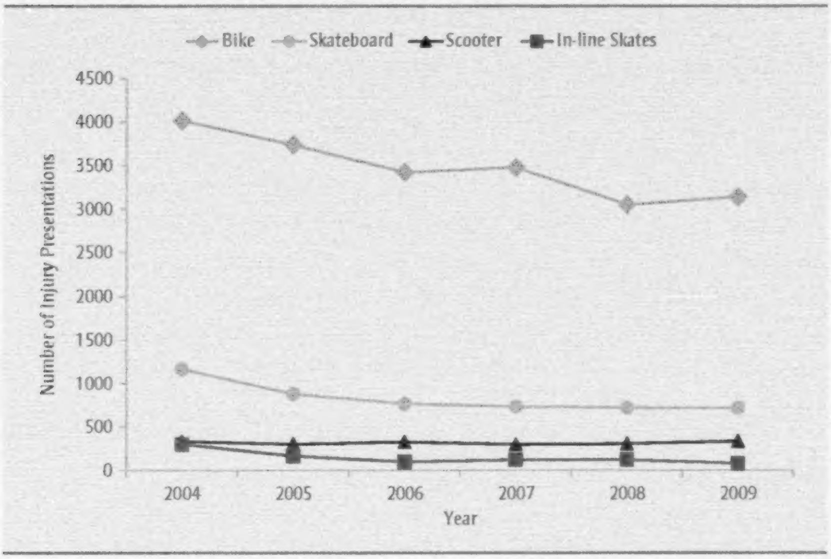
Abbreviation: df, degrees of freedom.

[a] Sex by activity: $\chi^2 = 959.2$, df = 3, $p < .001$.

[b] Age by activity: $\chi^2 = 2375.4$, df = 9, $p < .001$.

[c] Data on sex was missing for 3 patients, 1 for cyclists and 2 for skateboarders.

FIGURE 1
Number of injury presentations by non-motorized wheeled activity, per year, 2004–2009, ages 1–16 years



data were missing was similar (within 3%) to that where helmet data were recorded. A higher proportion of 1 to 4 year olds (12.3% vs. 6.0%) were represented in the records missing helmet data; cyclists were represented less (68.8% vs. 74.3%) in the records missing helmet data.

Helmet use varied across non-motorized wheeled activities, with use being greatest among cyclists (62.2%) and then among in-line skaters (47.1%), scooter riders (39.7%) and skateboarders (32.9%). Other protective gear was used by only 4.1% of patients overall, and particularly among in-line skaters, at 12.7% of patients presenting. Across all activities and regardless of age or sex, children wearing helmets were less likely to experience a head injury compared with those not wearing a helmet (Table 4).

Among all the patients presenting with injuries from non-motorized wheeled activities, 2314 (8.1%) were admitted to hospital. Of the patients for whom helmet data were available, admitted patients were significantly less likely to be wearing a helmet, regardless of age or sex, compared with patients who were discharged home. When analyzed by activity type, however, this difference was only significant for cyclists (Table 4).

Helmet use and helmet legislation

Patients presenting to the ED with an injury from non-motorized wheeled vehicles in jurisdictions where helmet use is mandated had significantly lesser odds (OR = 0.86, 95% CI: 0.80–0.94) of having sustained a head injury, regardless of age and sex (Table 5). There was also an association between legislation and helmet use, as patients presenting in legislated jurisdictions had 2.12 times greater

TABLE 2
Type of injury by non-motorized wheeled activity, ages 1–16 years, 2004–2009

Injury type	Bicycle n (%)	Skateboard n (%)	Scooter n (%)	In-line skates n (%)	Total[a] n (%)	χ^2 (*df, p*)[b]
Superficial injuries	10 036 (38.0)	974 (17.4)	734 (33.2)	211 (21.8)	11 955 (34.0)	
Fractures	7446 (28.2)	2315 (41.5)	766 (34.6)	447 (46.1)	10 974 (31.2)	514.2 (3, < .001)
Musculoskeletal[c]	4836 (18.3)	1765 (31.6)	449 (20.3)	231 (23.8)	7281 (20.7)	
Head injury (minor)[d]	2278 (8.6)	293 (5.2)	122 (5.5)	40 (4.1)	2733 (7.8)	110.1 (3, < .001)
Head injury (severe)[e]	166 (0.6)	27 (0.5)	7 (0.3)	3 (0.3)	203 (0.6)	5.8 (3, < .12)
Dental	701 (2.7)	49 (0.9)	77 (3.5)	4 (0.4)	831 (2.4)	
Multiple or severe injuries[f]	420 (1.6)	35 (0.6)	10 (0.5)	4 (0.4)	469 (1.3)	53.6 (3, < .001)
Dislocations	143 (0.5)	52 (0.9)	9 (0.4)	9 (0.9)	213 (0.6)	
Other[g]	395 (1.5)	73 (1.3)	37 (1.7)	20 (2.1)	525 (1.5)	
Total[a]	26 421 (100)	5583 (100)	2211 (100)	969 (100)	35 184 (100)	

Abbreviation: df, degrees of freedom.

[a] Numbers represent total injury counts, patients may have more than one injury.

[b] χ^2 compares proportions across activity types.

[c] Musculoskeletal injuries, e.g. sprains.

[d] Minor head injuries include minor head injury and concussion.

[e] Severe head injuries include intracranial injuries.

[f] Multiple or severe injuries include traumatic amputation, injury to internal organ, crushing injury, multiple injuries of more than one nature, injury to blood vessels and to nerves.

[g] Other injuries include injuries to the eye, respiratory tract, alimentary tract and soft tissue; burns or corrosions; and unspecified injuries.

TABLE 3
Type of fracture by non-motorized wheeled activity, ages 1–16 years, 2004–2009

Type of fracture	Bicycle n (%)	Skateboard n (%)	Scooter n (%)	In-line skates n (%)	Total[a] n (%)	χ^2 (*df*, *p*)[b]
Elbow and forearm	3288 (44.2)	806 (34.8)	335 (43.7)	212 (47.4)	4641 (42.3)	
Wrist and hand	1860 (25.0)	695 (30.0)	251 (32.8)	175 (39.1)	2981 (27.2)	301.7 (3, < .001)
Clavicle, shoulder and upper arm	941 (12.6)	130 (5.6)	37 (4.8)	23 (5.1)	1131 (10.3)	
Hip and leg	562 (7.5)	200 (8.6)	70 (9.1)	21 (4.7)	853 (7.8)	
Ankle and foot	351 (4.7)	441 (19.0)	57 (7.4)	11 (2.5)	860 (7.8)	862.3 (3, < .001)
Head and face	338 (4.5)	37 (1.6)	15 (2.0)	3 (0.7)	393 (3.6)	
Neck and spine	53 (0.7)	3 (0.1)	1 (0.1)	1 (0.2)	58 (0.5)	
Trunk and pelvis	52 (0.7)	3 (0.1)	0 (0.0)	1 (0.2)	56 (0.5)	
Total[a]	7445 (100.0)	2315 (100.0)	766 (100.0)	447 (100.0)	10 973 (100.0)	

Abbreviation: df, degrees of freedom.

Note: Data on type of injury was missing for 1 cyclist.

[a] Numbers represent injury counts, patients may have more than one injury.

[b] χ^2 compares proportions across activity types.

odds of reporting helmet use (95% CI: 1.99–2.26).

Discussion

To our knowledge, this is the first epidemiological study that used Canada-wide data to compare injuries among users of non-motorized wheeled devices. It indicates that these injuries represent a significant proportion of the morbidity and ED use among pediatric patients and provides compelling evidence for the importance of helmet legislation for injury prevention.

Cycling accounted for most injuries, possibly as a result of its popularity: one Canadian survey found that 94% of children aged 5 to 12 years and 79% of children aged 13 to 17 years had ridden a bicycle in the previous 12 months.[14] In an annual survey done in the United States, 39.8% of all participants aged over 7 years reported bicycling, 7.7% skateboarding, 7.5% in-line skating and 7.4% using a scooter.[15] The same data showed that males made up 76% of skateboarders, 51% of in-line skaters, 56% of cyclists and 58% of scooter users.[16] However, they made up a disproportionate majority of those presenting with injury across all non-motorized wheeled activities. This may be due to boys' greater participation in certain activities[17] and/or differences in risk-taking behaviours.[18] While little is reported on the ages of the users of the wheeled activities, most previous studies on injury patterns have demonstrated a similar pattern of age distribution. Patients presenting with scooter-related injuries tended to be younger, and those presenting with injuries from skateboarding tended to be older.[3,6] However, studies including adult data suggest that skateboard and scooter use are more prevalent in children.[1,15] Almost

TABLE 4
Type of injury by non-motorized wheeled activity and helmet use, ages 1–16 years, 2004–2009

Activity	Head injury			Admission		
	Helmet[a] use n (%)	No helmet use n (%)	Adjusted[b] OR (95% CI)	Helmet use n (%)	No helmet use n (%)	Adjusted[b] OR (95% CI)
Bicycle	887 (46.1)	1035 (53.9)	0.43 (0.39–0.47)	687 (54.1)	583 (45.9)	0.63 (0.56–0.71)
Skateboard	39 (16.5)	198 (83.5)	0.33 (0.23–0.46)	56 (29.9)	131 (70.1)	0.78 (0.56–1.07)
Scooter	24 (27.6)	63 (72.4)	0.53 (0.33–0.86)	18 (40.0)	27 (60.0)	0.99 (0.55–1.85)
In-line Skates	8 (29.6)	19 (70.4)	0.33 (0.14–0.79)	6 (35.3)	11 (64.7)	0.51 (0.18–1.41)
Total	958 (42.1)	1315 (57.9)	0.49 (0.45–0.54)	767 (50.5)	752 (49.5)	0.74 (0.67–0.83)

Abbreviations: CI, confidence interval; df, degrees of freedom; OR, odds ratio.

[a] Helmet use by activity: $\chi^2 = 1185.3$, $df = 3$, $p < .001$.

[b] OR adjusted for age and sex.

TABLE 5
Helmet use and head injury from non-motorized wheeled activity by helmet legislation, ages 1–16 years, 2004–2009

Jurisdictions that have helmet legislation	Helmet use[a]		Adjusted[b] OR (CI)	Head injury[c]		Adjusted[b] OR (CI)	All injured patients	
	n	%		n	%		n	%
Yes[d]	9791	81.0	2.12 (1.99–2.26)	1894	65.9	0.86 (0.80–0.94)	19 776	69.1
No[e]	2304	19.0		982	34.1		8842	30.9
Total	12 095	42.3[f]		2876	10.0[f]		28 618	100.0

Abbreviations: CI, confidence interval; df, degrees of freedom; OR, odds ratio.

[a] Helmet use by legislation: $\chi^2 = 491.6$, $df = 1$, $p < .001$, data on helmet use excluded patients with no data for helmet use.

[b] OR adjusted for age, sex and non-motorized wheeled activity.

[c] Head injury by province: $\chi^2 = 15.6$, df = 1, $p < .001$.

[d] Jurisdictions with legislation: British Columbia, Alberta, Ontario, Nova Scotia, and St. John's (Newfoundland and Labrador).

[e] Jurisdictions without legislation: Nunavut, Manitoba, Quebec.

[f] Percentage of the total of injured patients.

all studies demonstrate that the majority of injury presentations from non-motorized wheeled activities occur among those aged between 9 and 14 years.[3,6,19] The decrease seen in injury presentations among cyclists may be due to a decrease in use over the same time period[20] or may be due to successful injury prevention efforts.

Falls far exceeded other mechanisms of injury regardless of activity type. MVCs represented a very small portion, even for bicycle-related injuries, although due to the tendency for severe injuries to bypass the ED, these may not be well represented in CHIRPP. In any case, our findings suggest that, while traffic navigation skills are important in keeping children safe, the use of helmets and other safety gear that protect children when they do fall are justified, as are engineering strategies that reduce the likelihood of falls. Evidence shows that wrist guards, elbow pads and knee pads can protect against certain injuries, specifically wrist and forearm fractures, elbow injuries and knee injuries.[21,22] The most common injuries seen in our study across all activities were fractures, with elbow and forearm fractures predominating, and then wrist and hand fractures; such a pattern corresponds with findings from other research.[6] This suggests that many of the injuries that wheeled-activity users experience could be prevented with the use of protective gear, which is in fact recommended by the American Association of Pediatrics.[23] However, the overall use of protective gear was low across all activities, indicating an opportunity to intervene in an at-risk population.

Head injuries remain a significant cause of morbidity from non-motorized wheeled activities. Cyclists had the greatest proportion of head injuries, and in-line skaters the smallest. Fortunately, the rate of severe head injury remains low, although the proportion of severe head injury did not differ across activities, suggesting that the potential for severe head injury remains significant regardless of the type of non-motorized wheeled activity. Further, as more is understood about sport-related concussion and head injury,[24,25] patients presenting with even minor head injuries represent an opportunity to mitigate long-term consequences with appropriate education.

Our findings suggest that helmet use is associated with decreased likelihood of both head injury and admission. Further, the fact that hospitals in jurisdictions mandating helmet use had significantly higher proportion of helmet use and lower odds of head injury compared with those jurisdictions without helmet legislation suggests that legislation mandating helmet use increases helmet use and decreases the likelihood of head injury. Previous Canadian research has both demonstrated that helmet legislation reduces the rate of head injury in cyclists and that children's cycling rates increased after helmet legislation was introduced, suggesting that the protective effect of helmets is not the result of decreased cycling activity.[10] As of 2010, six provinces had mandatory helmet legislation for cyclists under age 18 years, although enforcement may vary by region and is difficult to measure.[12] The remaining seven provinces/territories have no legislation, although individual cities may have by-laws requiring the use of helmets, as is the case in St. John's (N.L.), where the CHIRPP hospital is located (although some of the patients presenting may have come from regions outside of the legislated area where helmet use is not mandated). Nova Scotia is the only province to enact a law requiring helmet use for all non-motorized wheeled activities.[12]

Overall, helmet use in this study was only 55% (for cases with available data), which is comparable to rates calculated in a similar manner in other studies,[6] including data reported by CHIRPP.[8] It may be that children wearing helmets are less likely to be injured and therefore present to an ED, or it may be related to how the information is collected at each hospital.

Strengths and limitations

As we were using retrospective data, our data and inferences are limited by how the forms were filled out by patients and physicians. The main limitation to this study was that we could not calculate rates of injuries for all users of non-motorized wheeled devices. The number of injuries seen is highly dependent on the frequency of use of each device and not representative of the incidence of injury from the activity.

Further, patients presenting at CHIRPP hospitals may not be representative of all users of non-motorized wheeled activities. Most CHIRPP hospitals are found in urban settings and only represent a small number of total injuries presenting to healthcare. Patients presenting to other hospitals, walk-in clinics or family doctors are not captured. However, research suggests that CHIRPP data for sports and recreation activities in particular may be representative of the Canadian population.[26,27] As well, using national data over a six-year period increased the statistical power of our data. The CHIRPP surveillance data represent the most extensive data source available from EDs across Canada, and are useful for describing the epidemiology of injured patients.

Conclusion

This study and other research support legislation mandating helmet use as an effective way of reducing injury in users of non-motorized wheeled activities. In addition, the ED may present a unique opportunity to prevent injury; past work has found that patients were receptive to information on preventing injury[28] and more likely to modify behaviours after counselling in the ED.[29] Studies have demonstrated that providing helmets or safety equipment such as booster seats, or having them conveniently available for purchase, increases reported use of safety devices.[30,31] Children presenting to the ED with injuries may represent a significant opportunity to address and encourage safety recommendations.

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Intentional injury hospitalizations in geographical areas with a high percentage of Aboriginal-identity residents, 2004/2005 to 2009/2010

L. N. Oliver, PhD; P. Finès, PhD; E. Bougie, PhD; D. Kohen, PhD

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Abstract

Introduction: This study describes rates of self-inflicted and assault-related injury hospitalizations in areas with a relatively high percentage of residents identifying as First Nations, Métis and Inuit, by injury cause, age group and sex.

Methods: All separation records from acute in-patient hospitals for Canadian provinces and territories excluding Quebec were obtained from the Discharge Abstract Database. Dissemination areas with more than 33% of residents reporting an Aboriginal identity in the 2006 Census were categorized as high-percentage Aboriginal-identity areas.

Results: Overall, in high-percentage Aboriginal-identity areas, age-standardized hospitalization rates (ASHRs) for self-inflicted injuries were higher among females, while ASHRs for assault-related injuries were higher among males. Residents of high-percentage Aboriginal-identity areas were at least three times more likely to be hospitalized due to a self-inflicted injury and at least five times more likely to be hospitalized due to an assault-related injury compared with those living in low-percentage Aboriginal-identity areas.

Conclusion: Future research should examine co-morbidities, socio-economic conditions and individual risk behaviours as factors associated with intentional injury hospitalizations.

Keywords: Aboriginal, injuries, intentional injuries, self-inflicted injuries, assault

Introduction

Aboriginal people in Canada (i.e. First Nations, Métis and Inuit) generally experience poorer health and lower life expectancy than the overall Canadian population;[1-9] they also experience higher rates of mortality and morbidity due to injuries.[10-12] Injuries are important to study because they are considered largely preventable, have long-term health effects and are associated with high health care costs.[3,4,13] Intentional injuries—which can be divided into self-inflicted and assault-related injuries—are particularly relevant to the Aboriginal population as several studies have shown higher rates of mortality due to suicide and homicide among First Nations and Métis populations.[2-5] For example, rates of mortality due to suicide or self-inflicted injury among residents of Inuit Nunangat, which has a predominant Inuit population, are at least 11 times higher than that of the rest of Canada.[6,7]

While mortality data is commonly used to examine intentional injuries, hospitalization data is also important because many intentional injuries do not result in death and are associated with co-morbidities (e.g. mental health diagnoses). As an illustration of the importance of hospitalization data, self-inflicted injury hospitalization rates have been found to be higher among females[8,14,15] while mortality data show higher rates of suicide among males.[15,16]

Individual Aboriginal identifiers are not routinely available on national hospitalization databases that contain injury information. As a result, existing studies tend to either use selected provincial databases that do contain identifying information or make use of a geographical approach. Provincial studies that use hospitalization data containing individual Aboriginal identifiers have been limited to those of the western provinces, where there is information on people registered under the Indian Act. These studies have found higher rates of self-inflicted and assault-related injury hospitalizations for registered First Nations compared to the general population.[1,8,9] However, these studies exclude Métis, Inuit and non-registered First Nations people.

Studies that use a geographical approach have found higher rates of intentional injury hospitalization in regions with a high percentage of Aboriginal-identity residents. A national study (excluding Quebec) found that areas with populations reporting predominant Aboriginal identity had rates of assault-related and self-inflicted injury hospitalizations that were, respectively, nine and six times higher than rates in areas with a low percentage of Aboriginal-identity residents.[10] Hospitalizations due to assaults

Author reference:

Health Analysis Division, Statistics Canada, Ottawa, Ontario, Canada

Correspondence: Philippe Finès, Health Analysis Division, RH Coats Building, Section 24A, 100 Tunney's Pasture Drive, Statistics Canada, Ottawa, Ontario, K1A 0T6; Tel.: 514-283-6847; Fax: 514-283-9350; Email: philippe.fines@statcan.gc.ca

were at least 17 times higher, and rates for self-inflicted injuries were at least six times higher in First Nations communities compared to southern municipalities in Ontario.[11] Relatively little information exists on intentional injury hospitalizations for the Inuit population, though higher rates of violent crimes, suicide mortality and unintentional injury hospitalization in Inuit communities have been documented.[6,7,17] Injury was recently identified as a gap in Métis-related health research.[12] While we found no studies examining hospitalizations for self-inflicted or assault-related injuries for the Métis population, one recent study showed higher self-reported suicide ideation among Métis people compared with non-Aboriginal people.[18]

Our analysis, which uses national data and a geographical approach, examines intentional injury hospitalizations for children and adults who live in areas where at least 33% of the residents report an Aboriginal identity. The purpose of our study is two-fold: (1) to calculate rates of self-inflicted and assault-related injury hospitalization in areas with a relatively high percentage of First Nations–, Métis- and Inuit-identity residents by age group and sex, and (2) to compare those rates to areas with a relatively low percentage of Aboriginal-identity residents. This study differs from others[10,17,19] as it takes a national focus on intentional injuries, examines different causes of injury and compares results for areas with a high and with a low percentage of people identifying as Aboriginal.

Methods

This study uses the same database and methodology as reported in a previous study focusing on hospitalizations for unintentional injuries.[20]

Hospitalization data

Hospitalization data for six fiscal years, 2004/2005 to 2009/2010, came from the Discharge Abstract Database.[21] This file contains information on all in-patient acute-care hospital separations (due to discharges, deaths, sign-outs and transfers) in the Canadian provinces and territories excluding Quebec. For each separation, information is available on age, sex, residential postal code, the date of admission and discharge and diagnoses codes based on the *International Classification of Diseases 10th Revision, Canadian version* (ICD-10-CA).[22]

We examined two categories of intentional injuries: self-inflicted injuries, which are purposely inflicted on oneself, and assaults, which are purposely inflicted to another person but exclude those due to war or legal intervention. Self-inflicted injuries were classified into cutting/piercing, drowning/suffocation and poisoning, whereas assault injuries were classified into cutting/piercing, struck by/against and sexual assault/maltreatment. Other categories of self-inflicted and assault-related injuries (such as falls, fire/hot substance, firearms or land transportation) were not analysed due to the small sample sizes. All categories with the exception of sexual assault/maltreatment were derived from the International Collaborative Effort on Injury Statistics ICD codes. Examples for each category of intentional injury are available on request.

Individuals transferred between facilities have multiple hospital separation records for a single injury episode, which can cause a single injury event to be counted more than once. To avoid multiple counting, any patient that was discharged and re-admitted to another facility on the same day was counted as a single episode. Data represent injury episodes rather than the number of individuals as it is possible that an individual was hospitalized more than once over the six-year period. Finally, episodes with multiple types of injuries could count towards multiple categories if applicable (e.g. self-inflicted as poisoning and cutting/piercing).

Geozones method

Dissemination areas (DAs) are small geographical units with a population between 400 and 700.[23] DAs with more than 33% of residents reporting an Aboriginal identity in the 2006 Census were classified as high-percentage Aboriginal-identity areas and further classified as First Nations, Métis or Inuit based on the predominant Aboriginal group. This area-based method has been used previously;[10,17] further information is available elsewhere.[24] Residential postal codes on the hospital separation records were used to determine the DA of residence via the Postal Code Conversion File Plus.[25]

In 2006, there were 38 869 DAs in Canada (excluding Quebec) that had less than 33% of residents reporting an Aboriginal identity, that is, low-percentage Aboriginal-identity areas. Among the 2174 DAs where more than 33% of residents reported an Aboriginal identity, 1929 were high-percentage First Nations–identity areas, 186 were high-percentage Métis-identity areas and 59 were high-percentage Inuit-identity areas.

These four types of areas—high-percentage First Nations–, Métis- and Inuit-identity DAs and low-percentage Aboriginal-identity DAs—differ according to several socioeconomic characteristics. As shown in Table 1, low-percentage Aboriginal-identity DAs are generally more affluent than high-percentage Aboriginal-identity DAs.

Analyses

Age-standardized hospitalization rates (ASHR) were calculated over the 6-year period (2004/2005–2009/2010) and were standardized to the age-structure of the 2006 Aboriginal-identity population in 5-year age intervals (i.e. they were computed as the weighted sum of age-specific hospitalization rates, where weights correspond to the proportion that each age group represents in the age-structure of the reference population). The denominator used to calculate the rates was from the 2006 census, which corresponds to the midpoint of the hospitalization data and was multiplied by six to calculate ASHRs for the 6-year period. ASHRs (per 10 000 person years) were calculated for five age groups (0–9, 10–19, 20–29, 30–44 and ≥ 45 years) and by sex for high-percentage First Nations–, Métis- and Inuit-identity areas and for low-percentage Aboriginal-identity areas. Since hospitali-

TABLE 1
Demographic and socio-economic 2006 census characteristics, by Aboriginal-identity group in dissemination area, Canada (excluding Quebec)

	High-percentage First Nations–identity DAs[a]	High-percentage Métis-identity DAs[a]	High-percentage Inuit-identity DAs[a]	Low-percentage Aboriginal-identity DAs
Number of DAs, n	1288	178	56	38 710
Total population, n	419 699	78 173	39 948	23 217 988
Population with an Aboriginal identity, %	79.9	54.7	81.4	2.8
Population living in crowded conditions, %	19.7	8.1	27.4	3.2
Population living in dwellings in need of major repairs, %	36.7	20.5	23.7	6.9
Population aged 25–64 years without a high school diploma, %	42.1	32.6	41.5	14.4
Population aged > 15 years who are unemployed, %	20.0	12.3	16.5	6.2
Population aged ≥ 15 years who are in the labour force, %	55.5	63.6	66.3	67.7
DA in CMA/CA	21.8	27.4	0.0	78.9
DA outside strong / moderate MIZ[b]	6.8	14.0	0.0	11.8
DA outside weak / no MIZ[b]	71.3	58.6	100.0	9.3
Mean household income (SD), $	22 512 (10 541)	32 163 (10 517)	41 252 (14 528)	47 406 (25 792)

Source: 2006 Census.

Abbreviations: CMA/CA, Census Metropolitan Area / Census Agglomeration; DA, Dissemination Area; MIZ, Metropolitan Influence Indicator.

Note: This table is built only on the DAs for which those characteristics were available.

[a] DAs where at least 33% of the population reported Aboriginal identity are classified as high-percentage Aboriginal identity. Classification as high-percentage First Nations, Métis or Inuit is based on the predominant Aboriginal group.

[b] The MIZ assigns a category to municipalities outside of a CMA/CA based on the percentage of the employed labour force that commute to work in the CMA/CA.

zations for self-inflicted injuries were rare among children aged 0 to 9 years, they were not analysed. Due to small populations, global non-response or incompletely enumerated Indian Reserves, a small number of DAs lacked the detailed age and sex data required for age-standardization. For these DAs, age and sex were estimated from total population counts or population estimates of incompletely enumerated Indian reserves. Rate ratios (RRs) compare the rates in high-percentage First Nations–, Métis- and Inuit-identity areas to rates in low-percentage Aboriginal-identity areas. We based confidence intervals (CIs) for rates and rate ratios on a log-normality assumption using the method specified in Kegler.[26] Two rates or rate ratios were considered significantly different if their 95% confidence intervals did not overlap. All analyses were done using statistical package SAS version 9.1.3 (SAS Institute Inc., Cary, NC, US).

Results

Table 2 shows descriptive statistics for the sample and the counts for self-inflicted and assault-related injury hospitalizations. Females had more hospitalizations for self-inflicted injuries than did males, whereas males had more hospitalizations for assault-related injuries. For self-inflicted injuries, the three most common causes were poisoning (86%), cutting/piercing (9%) and drowning/suffocation (2%) (Table 3). For assault injuries, the three most common causes were struck by/against (60%), cutting/piercing (20%) and sexual assault and maltreatment (7%); struck by/against was the most frequent cause among each type of area for both sexes, while cutting/piercing was second among males and sexual assault and maltreatment was second among females (Table 4).

Hospitalizations due to self-inflicted injuries

Across all areas (high- and low-percentage Aboriginal-identity), self-inflicted ASHRs for all causes combined were significantly higher for females than for males (Table 3) for all ages combined and all age groups. For example, the ASHR for causes combined and for age groups combined ranged from 6.2 per 10 000 person-years [95% CI: 6.2–6.3] (low-percentage Aboriginal-identity area) to 44.0 per 10 000 person-years [95% CI: 40.5–47.9] (high-percentage Inuit-identity area) for females, and from 3.8 [95% CI: 3.7-3.8] (low-percentage Aboriginal-identity area) to 21.5 [95% CI: 19.1–24.2] (high-percentage Inuit-identity area) for males.

For all causes combined and for all ages combined, RRs show that for both males and females, the ASHRs of self-inflicted injury hospitalizations in high-percentage First Nations–, Métis- and Inuit-identity areas were at least 2.5 times those observed in low-percentage Aboriginal-identity areas (Figure 1). RRs were highest for high-percentage Inuit areas where ASHRs for self-inflicted injuries among males and females were over 5 times those observed in low-percentage Aboriginal-identity areas.

ASHRs for self-inflicted injuries tended to peak among 20- to 29-year-olds for both males and females; however this age-related peak was statistically significant only in high-percentage First Nations–identity areas. The lowest self-inflicted

TABLE 2

Counts and descriptive statistics for intentional injury hospitalizations, by sex, dissemination area reporting Aboriginal identity, age group, and leading causes of injury, Canada (excluding Quebec), 2004/2005–2009/2010

Descriptive statistics	Self-Inflicted		Assault	
	Number	%	Number	%
Total (all causes)	77 497		43 854	
Sex				
Females	47 341	61.1	8376	19.1
Males	30 156	38.9	35 478	80.9
DA identity group				
High-percentage First Nations–identity	5424	7.0	7682	17.5
High-percentage Métis-identity	622	0.8	774	1.8
High-percentage Inuit-identity	781	1.0	480	1.1
Low-percentage Aboriginal-identity	70 670	91.2	34 918	79.6
Age group, years				
0–9	x	x	1272	2.9
10–19	13 545	17.5	7189	16.4
20–29	16 156	20.8	14 505	33.1
30–44	23 837	30.8	12 715	29.0
≥ 45	23 931	30.9	8173	18.6
Leading causes of injury				
Poisoning	66 724	86.1	—	—
Cutting/piercing	6956	9.0	8917	20.3
Drowning/suffocation	1464	1.9	—	—
Struck by/against	—	—	26 211	59.8
Sexual assault and maltreatment	n/a	n/a	3108	7.1

Source: Discharge Abstract Database 2004/2005–2009/2010.

Abbreviation: DA, Dissemination Area.

Notes: "x" indicates that the data was suppressed to meet the confidentiality requirements of the Statistics Act.

"—" indicates negligible data (small number of hospitalizations, not further analysed).

ASHRs were among those aged 45 years and over across all identity areas compared to the three younger age groups. Similarly, RRs were lowest in the 45 year plus age group compared to the three younger age groups; this was consistent across high-percentage First Nations–, Métis- and Inuit-identity areas (data not shown).

Self-inflicted poisoning, cutting/piercing and drowning/suffocation

There were differences in the types of self-inflicted injuries by sex and by Aboriginal-identity area (Table 3). For females, the majority of self-inflicted injuries were due to poisoning and the difference between high- and low-percentage Aboriginal-identity areas ranged only slightly, from 85% to 91%. The second most prevalent type of self-inflicted injury hospitalization for females was due to cutting/piercing, from 4% (high-percentage Inuit-identity areas) to 12% (high-percentage Métis-identity areas). The percentage of self-inflicted injury hospitalizations due to drowning/suffocation among females was less than 4% for all areas. For males, the majority of self-inflicted injury hospitalizations were also due to poisoning and ranged from 60% (high-percentage Inuit-identity areas) to 81% (low-percentage Aboriginal-identity areas). The proportion of hospitalizations due to cutting/piercing ranged from 11% to 15%, and the proportion of self-inflicted injury hospitalizations due to drowning/suffocation ranged from 3% (low-percentage Aboriginal-identity areas) to 9% (high-percentage Inuit-identity areas).

Some causes of self-inflicted injuries presented large disparities between high- and low-percentage Aboriginal-identity areas. More precisely, while overall rates were low, males and females living in high-percentage First Nations– and high-percentage Inuit-identity areas were at least 9 times more likely to be hospitalized for self-inflicted injuries due to drowning/suffocation compared to low-percentage Aboriginal-identity areas (Figure 1). Further, some RRs for self-inflicted injuries due to cutting/piercing were higher than the overall RR for all causes combined. This was the case for males in high-percentage First Nations–identity areas (RRs = 5.1 versus 3.8) and females in high-percentage Métis-identity areas (RRs = 4.6 versus 3.1). Females living in high-percentage Inuit-identity areas had a RR for cutting/piercing that was lower than the overall RR for self-inflicted injury hospitalizations (RRs = 3.7 versus 7.1). Turning to self-inflicted poisoning, the RR for males in high-percentage Inuit-identity areas was lower than the overall RR for self-inflicted injuries (RRs = 4.2 versus 5.7). Also, RRs for self-inflicted poisoning were higher for females than males in high-percentage First Nations– and high-percentage Inuit-identity areas.

Hospitalizations due to assault-related injuries

ASHRs for assault-related injuries were higher among males than females, and this was consistent across high- and low-percentage Aboriginal-identity areas (Table 4). For example, among males, the ASHR for all causes combined ranged from 4.6 per 10 000 person-years (95% CI: 4.5–4.6) in low-percentage Aboriginal-identity areas to 44.3 per 10 000 person-years (95% CI: 43.1–45.4) in high-percentage First Nations–identity areas; among females, the rates ranged from 0.9 (95% CI: 0.9–0.9) in low-percentage Aboriginal-

TABLE 3

Age-standardized hospitalization rates per 10 000 person-years for self-inflicted injuries, by age, sex, top injury causes and Aboriginal-identity group dissemination areas

Injury category	Aboriginal Identity Area[a]	Percentage of injury category within sex and area, all ages, %	Age, years									
			All		10–19		20–29		30–44		≥ 45	
			Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI
Females												
Total self-inflicted (all causes combined)	High % First Nations	100	28.44	27.53–29.39	40.52	39.12–43.07	49.67	46.61–52.94	40.29	37.97–42.74	15.98	14.63–17.45
	High % Métis	100	19.14	17.37–21.09	28.73	23.91–34.51	36.10	29.92–43.56	22.67	18.84–27.28	11.72	9.38–14.64
	High % Inuit	100	44.04	40.46–47.95	80.82	70.43–92.73	90.56	78.11–105.01	50.18	42.17–59.71	12.72	8.89–18.20
	Low % Aboriginal	100	6.25	6.19–6.31	9.02	8.83–9.22	9.36	9.16–9.56	8.05	7.91–8.19	5.10	5.01–5.19
Poisoning	High % First Nations	87	24.78	23.93–25.67	33.65	31.47–35.98	42.39	39.56–45.42	36.20	34.01–38.53	14.83	13.53–16.25
	High % Métis	85	16.18	14.57–17.97	22.67	18.44–27.88	28.38	22.97–35.06	21.45	17.73–25.95	10.44	8.25–13.21
	High % Inuit	91	40.20	36.78–43.94	74.46	64.52–85.94	80.26	68.58–93.92	46.50	38.83–55.68	11.92	8.22–17.27
	Low % Aboriginal	89	5.59	5.53–5.65	7.94	7.76–8.12	8.18	8.00–8.37	7.28	7.15–7.42	4.70	4.61–4.79
Cutting/piercing	High % First Nations	8	2.22	1.98–2.50	4.20	3.48–5.08	4.56	3.70–5.63	2.33	1.82–2.98	0.72	0.47–1.10
	High % Métis	12	2.24	1.68–2.99	4.52	2.85–7.18	6.06	3.82–9.61	x	x	x	x
	High % Inuit	4	1.79	1.18–2.73	x	x	x	x	x	x	x	x
	Low % Aboriginal	8	0.48	0.47–0.50	0.84	0.78–0.90	0.87	0.81–0.93	0.55	0.51–0.59	0.26	0.24–0.28
Drowning/Suffocation	High % First Nations	4	1.09	0.92–1.28	2.16	1.66–2.81	2.04	1.49–2.79	1.43	1.04–1.95	x	x
	High % Métis	x	x	x	x	x	x	x	x	x	x	x
	High % Inuit	2	1.02	0.58–1.80	x	x	x	x	x	x	x	x
	Low % Aboriginal	1	0.06	0.05–0.06	0.10	0.08–0.12	0.10	0.08–0.12	0.06	0.05–0.07	0.03	0.03–0.04
Males												
Total self-inflicted (all causes combined)	High % First Nations	100	14.39	13.75–15.06	13.13	11.83–14.58	32.19	29.71–34.89	22.71	20.96–24.59	9.22	8.24–10.32
	High % Métis	100	9.56	8.33–10.96	12.25	9.28–16.16	20.41	15.81–26.35	11.65	8.96–15.13	6.56	4.91–8.76
	High % Inuit	100	21.50	19.07–24.23	37.70	30.99–45.86	49.18	40.12–60.29	21.55	16.65–27.89	7.25	4.62–11.37
	Low % Aboriginal	100	3.77	3.73–3.82	3.09	2.98–3.20	6.34	6.18–6.51	6.04	5.92–6.17	4.03	3.95–4.11
Poisoning	High % First Nations	72	10.38	9.84–10.95	9.25	8.17–10.48	20.41	18.45–22.58	17.74	16.21–19.41	7.45	6.57–8.45
	High % Métis	74	7.06	6.02–8.28	9.31	6.77–12.79	14.21	10.46–19.29	8.73	6.45–11.82	5.05	3.62–7.04
	High % Inuit	60	12.90	11.06–15.06	21.08	16.23–27.40	28.61	21.90–37.37	14.96	10.97–20.41	4.59	2.61–8.10
	Low % Aboriginal	81	3.04	3.00–3.08	2.50	2.41–2.60	4.86	4.72–5.01	4.96	4.84–5.07	3.33	3.26–3.40
Cutting/piercing	High % First Nations	15	2.18	1.94–2.45	1.64	1.22–2.21	7.50	6.35–8.86	2.52	1.98–3.20	0.89	0.62–1.28
	High % Métis	14	1.35	0.93–1.95	x	x	5.18	3.12–8.60	x	x	x	x
	High % Inuit	11	2.43	1.71–3.46	x	x	7.27	4.30–12.28	x	x	x	x
	Low % Aboriginal	11	0.43	0.41–0.45	0.32	0.29–0.36	0.90	0.84–0.97	0.66	0.62–0.70	0.40	0.38–0.43

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TABLE 3 (continued)

Age-standardized hospitalization rates per 10 000 person-years for self-inflicted injuries, by age, sex, top injury causes and Aboriginal-identity group dissemination areas

Injury category	Aboriginal Identity Area[a]	Percentage of injury category within sex and area, all ages, %	Age, years									
			All		10–19		20–29		30–44		≥ 45	
			Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI
Drowning/Suffocation	High % First Nations	7	**1.07**	0.90–1.26	**1.79**	1.35–2.37	**2.44**	1.82–3.27	**1.17**	0.82–1.66	**0.32**	0.17–0.57
	High % Métis	5	**0.50**	0.27–0.94	x	x	x	x	x	x	x	x
	High % Inuit	9	**1.95**	1.31–2.88	x	x	**5.83**	3.23–10.54	x	x	x	x
	Low % Aboriginal	3	**0.11**	0.10–0.12	**0.14**	0.11–0.16	**0.22**	0.19–0.25	**0.14**	0.13–0.17	**0.09**	0.08–0.10

Source: Discharge Abstract Database 2004/2005–2009/2010.

Abbreviation: CI, confidence interval.

Notes: Two rates were considered significantly different if their 95% confidence intervals did not overlap.

"x" indicates that the data was suppressed to meet the confidentiality requirements of the Statistics Act.

[a] Dissemination areas where at least 33% of the population reported Aboriginal identity are classified as high-percentage Aboriginal identity. Classification as high-percentage First Nations, Métis or Inuit is based on the predominant group.

TABLE 4

Age-standardized hospitalization rates per 10 000 person-years for assault-related injuries, by age, sex, top injury causes and Aboriginal-identity group dissemination areas

Injury category	Aboriginal Identity Area[a]	Percentage of injury category within sex and area, all ages, %	Age, years											
			All		0–9		10–19		20–29		30–44		≥ 45	
			Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI
Females														
Total assault (all causes combined)	High % First Nations	100	**15.73**	15.05–16.44	**3.28**	2.65–4.06	**13.23**	11.89–14.72	**33.45**	30.95–36.15	**24.53**	22.75–26.46	**8.08**	7.16–9.13
	High % Métis	100	**8.27**	7.14–9.57	x	x	**6.56**	4.47–9.64	**16.53**	12.53–21.82	**13.02**	10.19–16.64	**4.55**	3.22–6.45
	High % Inuit	100	**16.81**	14.59–19.37	x	x	**6.75**	4.19–10.85	**28.90**	22.23–37.56	**31.66**	25.44–39.39	**14.40**	10.28–20.17
	Low % Aboriginal	100	**0.88**	0.85–0.90	**0.56**	0.51–0.62	**0.79**	0.74–0.85	**1.43**	1.36–1.51	**1.17**	1.12–1.23	**0.57**	0.54–0.60
Struck by/against	High % First Nations	57	**8.93**	8.42–9.46	x	x	**7.16**	6.19–8.28	**19.43**	17.55–21.51	**14.94**	13.56–16.46	**4.88**	4.17–5.71
	High % Métis	54	**4.46**	3.66–5.45	x	x	**3.04**	1.73–5.35	**10.25**	7.21–14.57	**7.33**	5.29–10.16	**2.76**	1.78–4.30
	High % Inuit	54	**9.08**	7.49–11.02	x	x	**4.36**	2.41–7.87	**17.58**	12.55–24.61	**14.83**	10.78–20.41	**8.88**	5.79–13.64
	Low % Aboriginal	45	**0.39**	0.38–0.41	**0.03**	0.02–0.04	**0.33**	0.30–0.37	**0.76**	0.71–0.82	**0.60**	0.56–0.64	**0.29**	0.27–0.31
Cutting/piercing	High % First Nations	12	**1.86**	1.64–2.12	x	x	**2.28**	1.76–2.94	**5.04**	4.13–6.16	**2.38**	1.86–3.03	**0.49**	0.29–0.81
	High % Métis	13	**1.11**	0.74–1.66	x	x	x	x	x	x	x	x	x	x
	High % Inuit	9	**1.57**	0.99–2.51	x	x	x	x	x	x	x	x	x	x
	Low % Aboriginal	12	**0.11**	0.10–0.12	x	x	**0.13**	0.11–0.16	**0.22**	0.19–0.25	**0.16**	0.14–0.18	**0.04**	0.04–0.05
Sexual assault/ Maltreatment	High % First Nations	19	**2.96**	2.68–3.27	**3.04**	2.44–3.79	**2.62**	2.06–3.33	**4.36**	3.51–5.40	**3.83**	3.16–4.64	**1.52**	1.16–2.00
	High % Métis	19	**1.55**	1.10–2.18	x	x	x	x	x	x	**2.44**	1.38–4.29	x	x
	High % Inuit	25	**4.16**	3.14–5.52	x	x	x	x	x	x	**8.72**	5.79–13.13	x	x
	Low % Aboriginal	30	**0.26**	0.25–0.27	**0.48**	0.43–0.53	**0.23**	0.20–0.26	**0.28**	0.24–0.31	**0.23**	0.20–0.25	**0.15**	0.13–0.16

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TABLE 4 (continued)

Age-standardized hospitalization rates per 10 000 person-years for assault-related injuries, by age, sex, top injury causes and Aboriginal-identity group dissemination areas

Injury category	Aboriginal Identity Area[a]	Percentage of injury category within sex and area, all ages, %	Age, years											
			All		0–9		10–19		20–29		30–44		≥ 45	
			Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI	Rate	95% CI
Males														
Total assault (all causes combined)	High % First Nations	100	**44.28**	43.14–45.44	**4.16**	3.45–5.01	**34.99**	32.82–37.31	**108.69**	104.04–113.55	**70.56**	67.44–73.83	**23.61**	22.01–25.33
	High % Métis	100	**27.40**	25.26–29.72	**3.10**	1.76–5.46	**24.72**	20.34–30.05	**64.88**	56.22–74.88	**43.44**	37.89–49.81	**12.98**	10.56–15.96
	High % Inuit	100	**22.88**	20.38–25.70	**6.58**	4.09–10.59	**12.36**	8.79–17.39	**49.91**	40.84–60.99	**36.71**	30.07–44.82	**17.51**	13.06–23.48
	Low % Aboriginal	100	**4.58**	4.53–4.63	**0.73**	0.68–0.79	**5.05**	4.91–5.19	**11.74**	11.52–11.97	**5.38**	5.26–5.50	**2.22**	2.16–2.28
Struck by/against	High % First Nations	60	**26.44**	25.56–27.34	**0.61**	0.37–0.99	**20.52**	18.87–22.31	**64.21**	60.66–67.97	**43.31**	40.88–45.89	**15.47**	14.18–16.87
	High % Métis	57	**15.70**	14.11–17.48	**x**	x	**14.18**	10.96–18.34	**37.45**	31.02–45.23	**27.18**	22.87–32.30	**6.55**	4.89–8.79
	High % Inuit	60	**13.71**	11.80–15.93	**x**	x	**6.37**	3.96–10.25	**31.88**	24.79–41.00	**24.79**	19.43–31.64	**10.80**	7.45–15.66
	Low % Aboriginal	61	**2.77**	2.73–2.81	**0.05**	0.04–0.07	**3.03**	2.93–3.14	**7.30**	7.13–7.48	**3.37**	3.28–3.47	**1.48**	1.43–1.53
Cutting/piercing	High % First Nations	25	**10.89**	10.33–11.48	**x**	x	**10.41**	9.26–11.71	**30.32**	27.91–32.94	**15.73**	14.29–17.32	**4.14**	3.50–4.91
	High % Métis	25	**6.97**	5.93–8.20	**x**	x	**6.62**	4.54–9.65	**19.80**	15.27–25.67	**8.90**	6.58–12.05	**3.26**	2.15–4.94
	High % Inuit	19	**4.36**	3.34–5.68	**x**	x	**x**	x	**9.73**	6.20–15.27	**6.75**	4.25–10.74	**3.88**	2.09–7.22
	Low % Aboriginal	22	**1.02**	1.00–1.05	**x**	x	**1.39**	1.32–1.47	**2.77**	2.66–2.88	**1.17**	1.12–1.23	**0.31**	0.29–0.34
Sexual assault/ Maltreatment	High % First Nations	2	**0.91**	0.76–1.08	**2.87**	2.29–3.58	**x**	x	**x**	x	**0.64**	0.40–1.03	**0.40**	0.24–0.65
	High % Métis	3	**0.84**	0.52–1.34	**x**	x	**x**	x	**x**	x	**x**	x	**x**	x
	High % Inuit	7	**1.52**	0.96–2.39	**5.42**	3.21–9.15	**x**	x	**x**	x	**x**	x	**x**	x
	Low % Aboriginal	3	**0.15**	0.14–0.16	**0.61**	0.56–0.67	**0.06**	0.05–0.08	**0.03**	0.02–0.04	**0.02**	0.01–0.03	**0.03**	0.02–0.04

Source: Discharge Abstract Database 2004/2005–2009/2010.

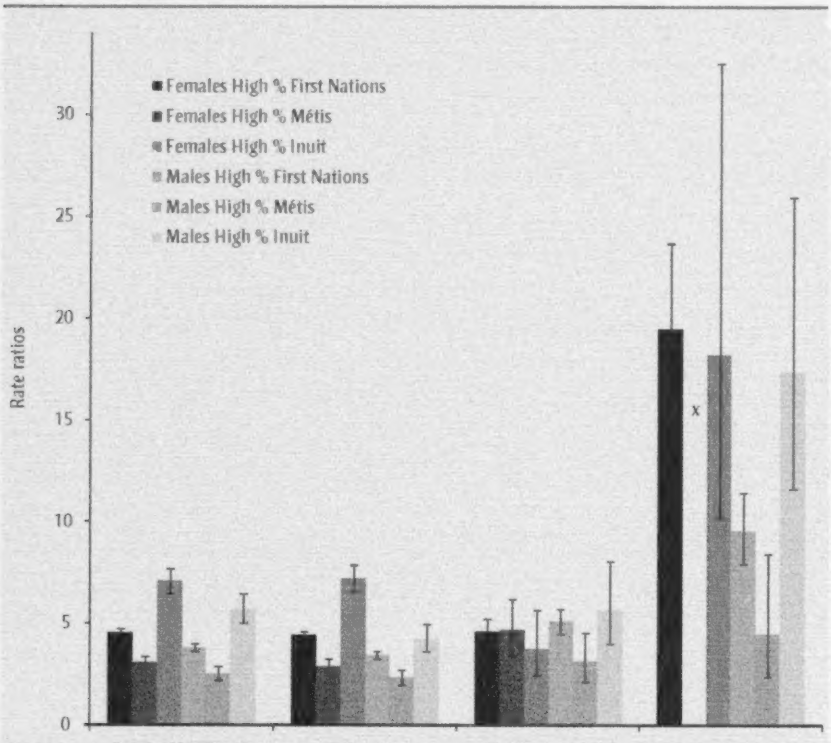
Abbreviation: CI, confidence interval.

Notes: Two rates were considered significantly different if their 95% confidence intervals did not overlap.

"x" indicates that the data was suppressed to meet the confidentiality requirements of the Statistics Act.

[a] Dissemination areas where at least 33% of the population reported Aboriginal identity are classified as high-percentage Aboriginal identity. Classification as high-percentage First Nations, Métis or Inuit is based on the predominant group.

FIGURE 1
Rate ratios for self-inflicted injuries, total age groups, by sex, top injury causes, and Aboriginal-identity group dissemination areas, Canada (excluding Quebec), 2004/2005–2009/2010



Notes: Reference group is Low % Aboriginal areas.

"x" indicates that the data was suppressed to meet the confidentiality requirements of the Statistics Act.

All rate ratios were statistically significant since their 95% confidence intervals did not include value 1.

identity areas to 16.8 (95% CI: 14.6–19.4) in high-percentage Inuit-identity areas.

However, RRs for all causes combined in high-percentage First Nations–, Métis- and Inuit-identity areas were higher among females than among males. RRs show that females living in high-percentage First Nations–identity areas were 17.9 times more likely to be hospitalized due to an assault than females in low-percentage Aboriginal-identity areas, and females in high-percentage Métis and high-percentage Inuit-identity areas were 9.4 and 19.2 (respectively) more likely to be hospitalized due to an assault. Among males, the RR for assault hospitalizations was 9.7 for high-percentage First Nations–, 6.0 for high-percentage Métis- and 5.0 for high-percentage Inuit-identity areas (Figure 2).

As with self-inflicted injuries, for both males and females across all areas, the ASHR for assault-related injuries tended to peak in the 20- to 29-year-old age group (data not shown). However, RRs comparing assault hospitalizations in high- and low-percentage Aboriginal-identity areas did not show a systematic pattern across age groups (data not shown).

Assaults by being struck, cut/pierced, and sexually assaulted/maltreated

The majority of assault-related injury hospitalizations were due to being struck, and this was consistent for both males and females across all areas (Table 4). RRs show that injury hospitalizations due to being struck was over 20 times higher among females living in high-percentage First Nations– and high-percentage Inuit-identity areas compared to low-percentage Aboriginal-identity areas for all ages combined (Figure 2). The RR for females living in high-percentage Métis-identity areas was somewhat lower. For males, injury hospitalizations due to being struck were approximately 10 times greater in high-percentage First Nations–identity areas and approximately five times greater in high-percentage Inuit- and high-percentage Métis-identity areas compared to low-percentage Aboriginal-identity areas.

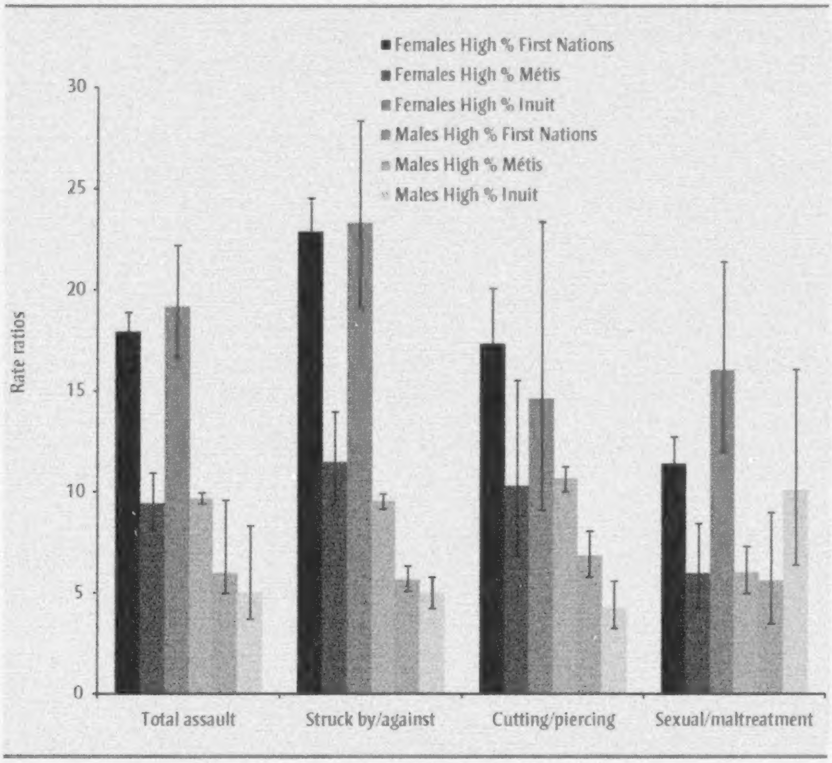
RRs show that assaults by being cut/pierced among males were approximately ten times higher in high-percentage First Nations–identity areas, seven times higher in high-percentage Métis-identity areas and four times higher in high-percentage Inuit-identity areas compared to low-percentage Aboriginal-identity areas. For females, even though the ASHR for this type of assault was low at less than 2 per 10 000 person-years across high- and low-percentage Aboriginal-identity areas (Table 4), assault hospitalizations due to cutting/piercing were respectively 17, 10 and 15 times higher in high-percentage First Nations–, Métis- and Inuit-identity areas compared to low-percentage Aboriginal-identity areas, for all ages combined (Figure 2).

Contrary to other types of assault, injury-hospitalizations due to sexual assault/maltreatment were higher for females than males across high- and low-percentage Aboriginal-identity areas. Still, RRs show that both males and females living in high-percentage First Nations–, Métis- and Inuit-identity areas were at least five times more likely to be hospitalized due to sexual assault/maltreatment than those living in low-percentage Aboriginal-identity areas (Figure 2).

Discussion

This study is important because it is the first to use Canadian national population-based hospitalization data to describe patterns of intentional injury hospitalizations for high-percentage First Nations–, Métis- and Inuit-identity areas compared to low-percentage

FIGURE 2
Rate ratios for assault-related injuries, total age groups, by sex, top injury causes, and Aboriginal-identity group dissemination areas, Canada (excluding Quebec), 2004/2005–2009/2010



Notes: Reference group is Low % Aboriginal areas.

All rate ratios were statistically significant since their 95% confidence intervals did not include value 1.

Aboriginal-identity areas. The use of six years of hospitalization data allowed us to produce rates by intentional injury cause, age and sex for high-percentage and low-percentage Aboriginal areas. These data are important to provide detailed information on differences in rates of intentional injury and can be used to track future changes over time. Overall, we found that hospitalization rates for self-inflicted injuries in high-percentage First Nations–, Métis- and Inuit-identity areas were at least three times those observed in low-Aboriginal-identity areas (for any sex, cause, age group), whereas hospitalization rates for assault-related injuries in high-percentage Aboriginal areas were at least five times those observed in low-percentage Aboriginal-identity areas (for any sex, cause, age group). These findings are consistent with other studies using national, provincial and individual data.[1,8-11] While a recent study that also used hospitalization data found higher rates of self-inflicted injury in neighbourhoods with lower socio-economic status,[27] our study cannot separate out these influences. High-percentage First Nations–, Métis- and Inuit-identity DAs have less affluent socio-economic conditions than low-percentage Aboriginal-identity DAs; trying to understand the impact of socio-economic conditions on rates of injury hospitalization for Aboriginal- and non-Aboriginal–identity areas is an important area for future research.

For males in high-percentage Aboriginal-identity areas, assault-related hospitalizations were between five and ten times higher than low-percentage Aboriginal-identity areas. Females living in high-percentage First Nations– and high percentage Inuit-identity areas were at particular risk of assault-related injury hospitalization, with rates at least 18 times higher than low-percentage Aboriginal-identity areas. RRs for females were highest for assaults due to being struck whereas females in high-percentage First Nations– and high-percentage Inuit-identity areas were over 20 times more likely to be hospitalized than females in low-percentage Aboriginal-identity areas. Similar results have been found for females living in First Nations communities in Ontario,[11] and indigenous females in Queensland, Australia.[28]

In this study, we found higher rates of self-inflicted injury hospitalization in high-percentage Aboriginal-identity areas, with poisoning, cutting/piercing and drowning/suffocation being the three leading causes of hospitalization. Rates of self-inflicted injury hospitalization were higher for females than males, and rates were highest for males and females living in high-percentage Inuit-identity areas. These findings are consistent with other Canadian[1,6,7,15] and international (New Zealand, Alaska, Greenland, Norway)[29,30] studies. These findings are also consistent with a study on self-reported suicide ideation, which showed higher prevalence of lifetime suicidal ideation and attempts among respondents reporting a Métis identity compared to non-Aboriginal respondents.[18]

Strengths and limitations

It is important to note that this is an ecological study reporting results for geographical areas. The associations observed should therefore be interpreted as applying to geographical areas only.

While a strength of this study was the use of six years of hospital separation data to provide information on intentional injury hospitalizations in high-percentage and low-percentage Aboriginal-identity areas, there are also some limitations of this data source. As individual Aboriginal identifiers were not available on hospital records, we used a 33% cut-off to define high-percentage Aboriginal-identity dissemination areas. As the populations of these areas consist of both Aboriginal and non-Aboriginal residents, the results are not generalizable to the First Nations, Métis and Inuit populations in Canada. While the geographical identifiers on the hospital separation records indicate the postal code of the individual's residence, the location where the injury occurred was not available. However, information on the location of self-reported injuries exists elsewhere.[31]

Hospitalization data from Quebec were not available, and in-patient hospitalization data included here are not representative of all serious or medically treated self-inflicted or assault-related injuries.[15] For example, this study did not capture information on the most serious intentional injuries (i.e. suicide, homicide) resulting in death prior to hospital admission. While the data used in this study did not determine if the intent of self-inflicted injury was self-harm or suicide, self-inflicted injuries have been described as markers of poor mental health and suicidality.[18,29,30,32-40]

Individuals presenting only to emergency departments but not admitted as inpatients were also excluded. It is also possible that some self-inflicted injuries were coded as "undetermined," thereby underestimating the actual rate of injury hospitalizations.[41] The hospitalization data also lacked individual-level socio-economic or behavioural information, which may explain individual risk factors for intentional injury hospitalization.[42]

Conclusion

This study has demonstrated that areas with a high percentage of residents identifying as Aboriginal (i.e. First Nations, Métis and Inuit) have higher rates of hospitalization due to self-inflicted and assault-related injury compared to areas with a low percentage of residents identifying as Aboriginal. This study is the first to examine intentional injury hospitalization by cause for area-based Aboriginal identity in Canada. Future research could examine injury severity, as there is some evidence that severity may differ between Aboriginal and non-Aboriginal populations.[9,43] Approximately 70% of inpatient hospitalizations for self-inflicted injuries also include a mental illness diagnosis,[15] suggesting the importance of future research examining co-morbidities, as mental health has been linked to self-inflicted injury hospitalizations.[36] Research should also examine area-based socio-economic conditions as well as individual risk behaviours as factors associated with both intentional injuries and hospitalizations.[15,42,44] Finally, the specific cultural, historical and environmental contexts that may explain higher rates of assault and self-inflicted injury hospitalizations in high-percentage Aboriginal-identity areas[36,37,45] would contribute to our understanding.

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Modelling preventive effectiveness to estimate the equity tipping point: at what coverage can individual preventive interventions reduce socioeconomic disparities in diabetes risk?

D. G. Manuel, MD (1, 2, 3, 4, 5); T. H. Ho, MSc (1); S. Harper, PhD (6); G. M. Anderson, MD, PhD (1, 7); J. Lynch, PhD (8, 9); L. C. Rosella, PhD (1, 2, 10)

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Abstract

Introduction: Most individual preventive therapies potentially narrow or widen health disparities depending on the difference in community effectiveness across socioeconomic position (SEP). The equity tipping point—defined as the point at which health disparities become larger—can be calculated by varying components of community effectiveness such as baseline risk of disease, intervention coverage and/or intervention efficacy across SEP.

Methods: We used a simple modelling approach to estimate the community effectiveness of diabetes prevention across SEP in Canada under different scenarios of intervention coverage.

Results: Five-year baseline diabetes risk differed between the lowest and highest income groups by 1.76%. Assuming complete coverage across all income groups, the difference was reduced to 0.90% (144 000 cases prevented) with lifestyle interventions and 1.24% (88 100 cases prevented) with pharmacotherapy. The equity tipping point was estimated to be a coverage difference of 30% for preventive interventions (100% and 70% coverage among the highest and lowest income earners, respectively).

Conclusion: Disparities in diabetes risk could be measurably reduced if existing interventions were equally adopted across SEP. However, disparities in coverage could lead to increased inequity in risk. Simple modelling approaches can be used to examine the community effectiveness of individual preventive interventions and their potential to reduce (or increase) disparities. The equity tipping point can be used as a critical threshold for disparities analyses.

Keywords: inequalities, public health, health impact assessment, diabetes

Introduction

The role of individual preventive therapy in reducing health disparities is the subject of current debate. One the one hand, health disparities may be reduced when relative treatment effects are constant across the spectrum of underlying risk.[1-3] If this assumption held true, the absolute community effectiveness from health interventions would be greater for disadvantaged groups compared to others because disadvantaged groups tend to have a higher baseline risk. Greater gains in absolute benefit for those in the lowest socioeconomic position (SEP) compared to those in higher SEP would therefore lead to a decrease in disparities between them.[1]

On the other hand, constant intervention efficacy should not be assumed and intervention coverage is often inequitable. Intervention coverage, defined as the proportion of the target population that is adherent to the intervention, encompasses the range of factors that affect the uptake of interventions, such as accuracy in identifying the target population, level of participation in the intervention and consumers' adherence.[4] Groups at a lower socioeconomic level tend to experience greater barriers in access to care, for example through income effects, or they may be less adherent to preventive therapies, for example, education effects.[5] Together, differences in efficacy and coverage undermine efforts to reduce disparities or else they can, perversely, increase disparities.[6]

In this study, we show how a simple modelling approach can be used to estimate

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Author references:

1. Institute for Clinical Evaluative Sciences, Toronto, Ontario, Canada
2. Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada
3. Ottawa Hospital Research Institute, Ottawa, Ontario, Canada
4. Statistics Canada, Ottawa, Ontario, Canada
5. Department of Family Medicine and Department of Epidemiology and Community Medicine, University of Ottawa, Ottawa, Ontario, Canada
6. Department of Epidemiology, Biostatistics and Occupational Health, McGill University, Montréal, Quebec, Canada
7. Department of Health Policy, Management, and Evaluation, University of Toronto, Toronto, Ontario, Canada
8. School of Population Health and Clinical Sciences, University of Adelaide, Adelaide, Australia
9. Department of Social and Community Medicine, University of Bristol, Bristol, United Kingdom
10. Public Health Ontario, Toronto, Ontario, Canada

Correspondence: Douglas G. Manuel, Ottawa Health Research Institute, 1-008 Admin Services Building, 1053 Carling Avenue, Ottawa, ON K1Y 4E9; Tel.: 613-798-5555, ext. 19108; Fax: 613-761-5492; Email: dmanuel@ohri.ca

the potential effectiveness of prevention interventions at reducing disparities (see Formula 1). We demonstrate this using diabetes prevention in Canada.

FORMULA 1

Community effectiveness = target population × baseline risk × intervention efficacy × intervention coverage*

Community effectiveness: the benefit, or absolute risk reduction, of preventive interventions in the real-world community setting.

Target population: the proportion of the population, or each sociodemographic strata, that is eligible for the preventive intervention.

Baseline risk: the risk or probability of developing a disease prior to intervention implementation.

Intervention efficacy: the relative benefit of an intervention as determined from intervention trials or other studies, i.e. ideal or controlled settings.

Intervention coverage: the proportion of the target population that is adherent to the intervention.

*Derived from the "evidence equity loop."[4]

The potential for interventions to reduce inequalities can be estimated when we calculate and compare community effectiveness for each socioeconomic stratum. Disease disparities will narrow if community effectiveness is larger for low socioeconomic groups compared to their higher SEP counterparts.

A common challenge when estimating community effectiveness for individual socioeconomic strata is the lack of information that is specific to the different strata, including variation in the target population size, baseline risk, intervention efficacy and coverage. For such situations, we introduce the concept of the "equity tipping point," defined as the point at which the disparity between highest and lowest socioeconomic strata becomes larger as a result of differences in intervention efficacy, coverage or target population. The objective when calculating the equity tipping point is to gauge whether potential differences realistically exist. In the example of diabetes prevention, we sought to identify the point at which intervention coverage gaps resulted in a widened disparity in diabetes risk. To show this better, we did not vary intervention efficacy or target population criteria.

We examined 2 types of diabetes prevention interventions that have well-established efficacy: lifestyle interventions and pharmacotherapy.[7] Lifestyle interventions reduce obesity through diet and exercise programs. Pharmacotherapy uses medications such as metformin to reduce weight and insulin resistance so as to reduce new cases of diabetes among those at risk. While these therapies appear to be efficacious across socioeconomic groups,[7,8] achieving high coverage for diabetes in particular and chronic diseases in general is a challenge[9,10] and the level of coverage likely varies across socioeconomic groups. However, we are unaware of any data about intervention coverage by SEP for diabetes prevention.

We estimated the equity tipping point in 2 steps. First, we calculated community effectiveness of lifestyle interventions and pharmacotherapy under a scenario of 100% coverage for all socioeconomic groups. This estimated the maximum or optimal reduction in diabetes disparity. Next, we incrementally reduced coverage in the lowest SEP until we reached the equity tipping point, or the point where there was no reduction in diabetes disparities.

Methods

The study was approved by the Research Ethics Board of Sunnybrook Health Sciences Centre, Toronto, Ontario. Figure 1 shows the steps taken to select an eligible target population and evaluate the impact of health interventions on socioeconomic disparities in diabetes risk.

Data sources and cohort selection

We used data from the 2005 Canadian Community Health Survey (CCHS) to obtain Canadians' self-reported diabetes status, SEP and other diabetes-related risk factors (n = 107 212, unweighted). The CCHS is a cross-sectional, population-based and nationally representative survey with self-reported information on health status and health determinants.[11] We identified all diabetes-free and non-pregnant Canadian adults from the CCHS.

Target population

We defined the target population for the preventive interventions using information from a meta-analysis of 17 efficacy studies that examined therapies that prevent or delay diabetes in adults.[7] Reflecting the range of participants' mean age and body mass index (BMI) from these 17 studies, we defined the target population as people aged 39 to 57 years with BMI values between 24 and 37 kg/m^2. The studies included in the meta-analysis showed the same efficacy in a wide range of populations and socioeconomic settings.

Baseline risk of developing diabetes

The five-year (2005–2010) baseline risk of diabetes by level of SEP was calculated using the Diabetes Population Risk Tool (DPoRT), a validated risk prediction algorithm.[12] We further evaluated the predictive accuracy of DPoRT for this study and found that diabetes incidence can be predicted with discrimination and accuracy across socioeconomic groups (see supplementary online appendix).

Preventive intervention efficacy

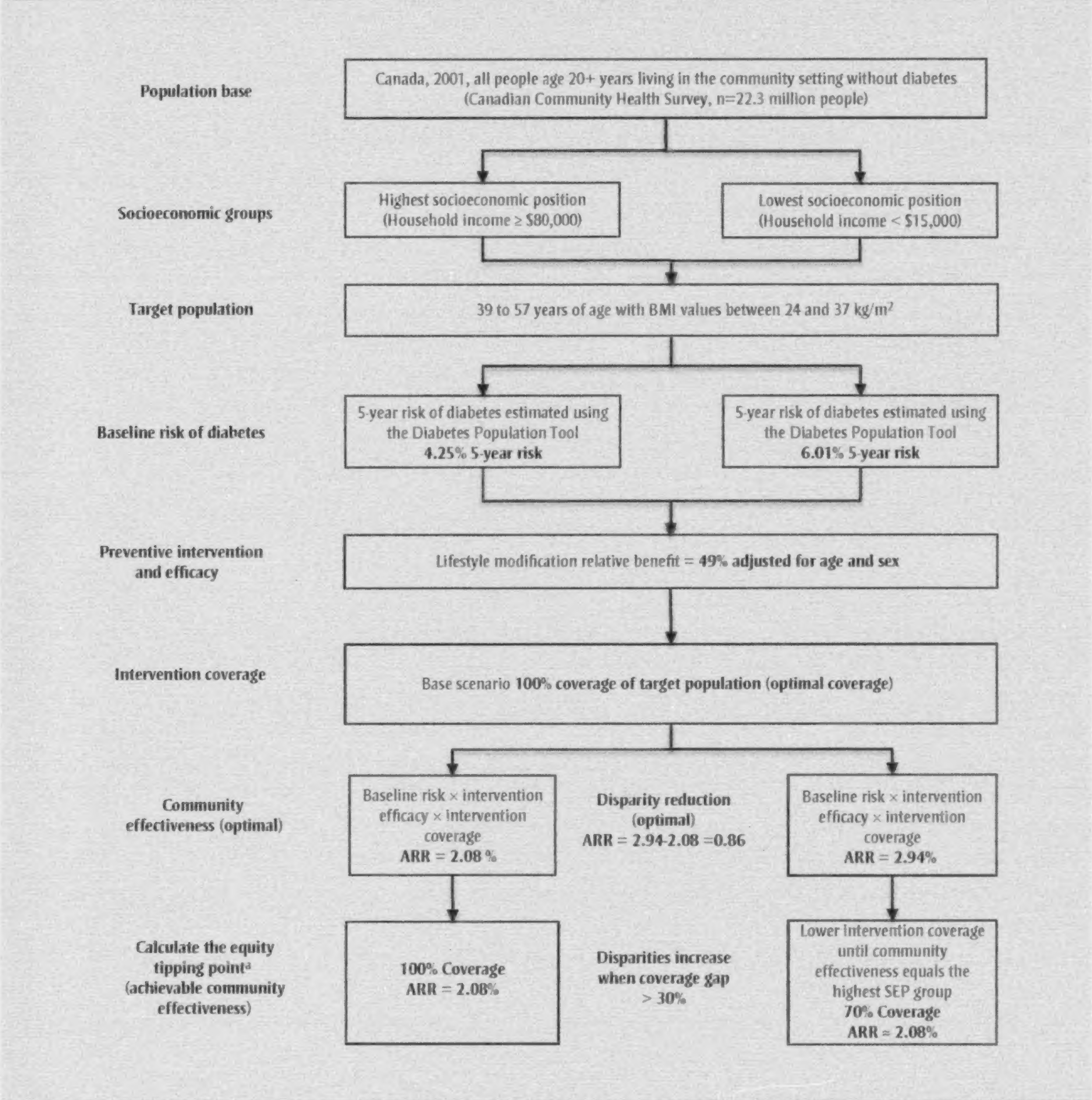
The intervention meta-analysis reported a 5-year pooled hazard ratio (HR) of 0.51 (95% CI: 0.44–0.60) for lifestyle interventions and of 0.70 (95% CI: 0.62–0.79) for medication interventions, demonstrating relative treatment effects of 49% and 30%, respectively. The meta-analysis did not examine whether efficacy varied by SEP.

Community effectiveness analyses

Using household income and respondent education as indicators of SEP, we calculated diabetes risk (and absolute risk reduction [ARR]) across SEP groups for baseline and post-intervention scenarios assuming 100% coverage. ARR was defined as the absolute difference between

FIGURE 1

Process to estimate the community effectiveness and the equity tipping point of preventive interventions for diabetes (lifestyle modification or pharmacotherapy). Example of reducing disparities across income groups using lifestyle modification


Population base
Canada, 2001, all people age 20+ years living in the community setting without diabetes (Canadian Community Health Survey, n=22.3 million people)
Socioeconomic groups
Highest socioeconomic position (Household income ≥ $80,000)
Lowest socioeconomic position (Household income < $15,000)
Target population
39 to 57 years of age with BMI values between 24 and 37 kg/m²
Baseline risk of diabetes
5-year risk of diabetes estimated using the Diabetes Population Tool 4.25% 5-year risk
5-year risk of diabetes estimated using the Diabetes Population Tool 6.01% 5-year risk
Preventive intervention and efficacy
Lifestyle modification relative benefit = 49% adjusted for age and sex
Intervention coverage
Base scenario 100% coverage of target population (optimal coverage)
Community effectiveness (optimal)
Baseline risk × intervention efficacy × intervention coverage ARR = 2.08 %
Disparity reduction (optimal) ARR = 2.94-2.08 =0.86
Baseline risk × intervention efficacy × intervention coverage ARR = 2.94%
Calculate the equity tipping point[a] (achievable community effectiveness)
100% Coverage ARR = 2.08%
Disparities increase when coverage gap > 30%
Lower intervention coverage until community effectiveness equals the highest SEP group 70% Coverage ARR = 2.08%

Abbreviations: ARR, absolute risk reduction; BMI, body mass index.

[a] The reduction in coverage (and/or baseline risk, efficacy or target population) where there is equal effectiveness between groups.

baseline and post-intervention diabetes risk. We defined disparity as the absolute difference in diabetes risk between the lowest and highest SEP groups. We then compared the baseline disparity to the post-intervention disparity to determine the absolute reduction. Finally, we examined how disparity was affected by sub-optimal intervention coverage. For ease of interpretation, we explored this scenario by maintaining widespread coverage among the highest SEP groups and varying the coverage among the lowest SEP groups. We calculated the equity tipping point by recalculating the ARR for the lowest SEP groups as we varied coverage, until we reached the same ARR as the highest SEP groups.

Results

Table 1 compares the baseline characteristics of adults in the target and non-target groups. The target population was predominantly male, and by definition, included mainly overweight or obese adults. The target population represented 32.8% of 22.3 million Canadians adults without diabetes.

The 5-year baseline risk of diabetes for Canada, 2001, was 4.78%. The risk of diabetes declined with increase in SEP, from 6.01% among the lowest income earners to 4.25% among the highest, demonstrating a baseline disparity of 1.76% between the lowest SEP and highest SEP groups. Table 2 shows the predicted risk of developing diabetes across socioeconomic strata, BMI and other demographic factors.

Table 3 shows how complete coverage of lifestyle or pharmacological interventions affected socioeconomic disparities in diabetes risk. The ARR associated with a lifestyle intervention was 2.34%. This reduced the disparity between the lowest and highest income earners from 1.76% to 0.90%. With pharmacotherapy, the ARR was 1.43%, which narrowed the disparity from 1.76% to 1.24%. Benefit can also be reported in terms of total cases of diabetes prevented in Canada (144 000 cases prevented with lifestyle interventions vs. 88 100 cases prevented with pharmacotherapy). There were fewer cases of diabetes prevented in the lower SEP strata compared to the highest strata, reflecting a smaller number of people in the low SEP strata (see Tables 1 and 2).

Figure 2 shows how the complete coverage of health interventions affects diabetes risk disparities across different levels of income and education. As expected, the disparity widens when the intervention coverage drops in the lowest SEP groups, but is maintained at 100% for the highest SEP groups. The equity tipping point is reached at 70% coverage for lowest income earners and 60% for lowest education groups. Below these coverage levels, there is progressive widening of diabetes risk between SEP groups.

TABLE 1

Baseline demographic, socioeconomic and anthropometric characteristics of diabetes-free adults, ≥ 20 years, Canadian Community Health Survey, 2005[a]

Characteristic	Target population[b] (N = 7 100 000) %	Non-target population (N = 15 200 000) %
Sex		
Men	60.1	43.4
Women	40.0	56.6
Age, years		
20–34	—	41.5
35–44	41.5	13.1
45–54	41.1	10.7
55–64	17.4	12.8
≥ 65	—	21.9
Household income, $		
< 15 000	3.5	6.4
15 000–29 999	7.1	15.1
30 000–49 999	16.8	21.6
50 000–79 999	29.1	26.3
≥ 80 000	43.4	30.6
Education		
< Secondary school	12.2	17.1
Secondary school graduate	16.3	15.8
Some post-secondary school	6.8	9.2
Post-secondary school graduate	64.7	57.9
Employment status		
Yes	88.1	74.8
No	11.9	25.2
Ethnicity		
Non-white	13.8	17.3
White	86.2	82.7
Immigrant		
Yes	20.8	22.8
No	79.2	77.2
BMI, kg/m^2		
Underweight (<18.50)	—	3.9
Normal weight (18.50–24.99)	20.6	61.1
Overweight (25.00–29.99)	57.2	23.6
Obese (≥ 30)	22.2	11.4

Abbreviation: BMI, body mass index.

[a] Results based on weighted estimates to account for survey design and population demographics.

[b] Adults aged 39–57 years with BMI 24.00–37.00 kg/m^2.

Discussion

Our study presents a straightforward modelling approach to estimate the potential reduction in socioeconomic disparities in disease risk using individual preventive interventions. In the considerable debate about whether individual interventions can or should have a role for reducing health disparities, the discussion is typically buttressed with either theoretical

TABLE 2
Five-year baseline risk and predicted number of new diabetes cases in the target population,[a] 2005–2010

Characteristic	Target population[a]	
	Number of cases,[b] n	Mean risk, %
Overall	323 000	4.78
Sex		
Men	193 000	4.77
Women	130 000	4.80
Age, years		
20–34	—	—
35–44	63 500	2.26
45–54	181 000	6.40
55–64	79 000	6.63
≥ 65	—	—
Household income, $		
< 15 000	11 800	6.01
15 000–29 999	24 700	5.55
30 000–49 999	53 800	5.05
50 000–79 999	85 700	4.59
≥ 80 000	118 000	4.25
Education		
< Secondary school	55 300	6.82
Secondary school graduate	62 300	5.60
Some post-secondary school	22 000	4.53
Post-secondary school graduate	184 000	4.10
Employment status		
Yes	272 000	4.54
No	48 800	6.21
Ethnicity		
Non-white	68 900	7.39
White	255 000	4.50
Immigrant		
Yes	87 100	5.87
No	236 000	4.63
BMI (kg/m^2)		
Underweight (< 18.50)	—	—
Normal weight (18.50–24.99)	30 500	2.05
Overweight (25.00–29.99)	153 000	3.81
Obese (≥ 30)	140 000	9.19

[a] Adults aged 39–57 years with BMI 24.00–37.00 kg/m^2.

[b] Based on weighted estimates accounting for survey design and population demographics.

arguments or examples from specific studies or populations.[13,14] In practice, most preventive interventions—whether they are individual-based or community-wide—have the potential to narrow or widen health disparities depending on the extent of disparities in baseline risk, intervention efficacy and intervention coverage. The ability to analytically examine the settings in which preventive interventions will likely narrow or widen health disparities is helpful for practical health planning and for more general discussions about disease prevention.

Rose[15] rightly indicated that an understanding of absolute measures of risk is a cornerstone of population health planning. However, the limitations of Rose's approach for evaluation of equity issues have been much debated.[6,13,16] Tugwell et al.[4] outlined a framework for considering equity issues when evaluating health policies. The modelling approach used here is similar to the "effectiveness equity loop" described by Tugwell et al.,[4] except that our calculations were specific to preventive interventions and used a multivariate risk tool to estimate baseline risk. As a measure the equity tipping point is also analogous to threshold or sensitivity analyses in economic studies where there is uncertainty or variation in costing of components and estimates of effectiveness.[17,18]

We varied only one component of community effectiveness—coverage—to examine its effect on the equity tipping point. We chose this variable because of concerns that coverage varies considerably across socioeconomic groups and because lower coverage of diabetes preventive therapies has been observed in low-income communities.[19] Intervention uptake is influenced by a complex array of individual, provider and health system factors—attitudes, language and cultural barriers, trust in the health care system, quality of the communication relationship and continuity of care[9,10,20-22]—all of which can have varied effects on intervention coverage.

As expected, we found that when intervention coverage decreased among those in the lowest SEP group, so did the ARR. We further demonstrated the potential for poor coverage to exacerbate baseline disparity in diabetes risk when the intervention coverage surpasses the equity tipping point. At this threshold, the difference in intervention coverage voided any equity benefit of the health intervention and led to an increased disparity in diabetes risk. In an attempt to explain this predicted effect, others have theorized that health interventions may increase disparities if advantaged groups are more likely than their poorer, less educated and unemployed counterparts to have the financial and knowledge resources to capitalize on available opportunities to improve health.[13,23]

TABLE 3

Impact of optimal (100%) coverage of lifestyle and pharmacological interventions on the disparity in diabetes risk

Household income, $	< 15 000	15 000–29 999	30 000–49 999	50 000–79 999	≥ 80 000	Overall	Disparity[a]	Absolute disparity reduction[b]
Baseline risk of diabetes, %	6.01	5.55	5.05	4.59	4.25	4.78	1.76	—
Lifestyle intervention								
Absolute risk reduction,[c] %	2.94	2.72	2.47	2.25	2.08	2.34	0.90	0.86
Cases prevented[d], n	5760	12 100	26 400	42 000	57 600	144 000		
Pharmacological intervention								
Absolute risk reduction[c], %	1.80	1.67	1.52	1.38	1.28	1.43	1.24	0.52
Cases prevented[d], n	3530	7420	16 100	25 700	35 300	88 100		

Education	< Secondary school	Secondary school graduate	Some post-secondary school	Post-secondary graduate	Overall	Disparity[a]	Absolute disparity reduction[b]
Baseline risk of diabetes, %	6.82	5.60	4.53	4.10	4.78	2.72	—
Lifestyle intervention							
Absolute risk reduction,[c] %	3.34	2.74	2.22	2.01	2.34	1.39	1.33
Cases prevented[d], n	27 100	30 500	10 800	90 100	159 000		
Pharmacological intervention							
Absolute risk reduction,[c] %	2.05	1.68	1.36	1.23	1.43	1.90	0.82
Cases prevented[d], n	16 600	18 700	6610	55 200	97 000		

[a] Disparity = diabetes risk of lowest socioeconomic group − diabetes risk of highest socioeconomic group

[b] Absolute disparity reduction = baseline disparity − post-intervention disparity

[c] Absolute risk reduction = baseline diabetes risk − post-intervention diabetes risk

[d] Number of cases is based on weighted estimates accounting for survey design and population demographics. The discrepancy in total number of cases prevented is due to missing information on income or education.

However, Anderson et al.[1] raised 2 relevant points: 1) the steeper the initial gradient in baseline risk, the larger the effect that suboptimal coverage would have to exert in order to annul the potential for health interventions to reduce health disparities; and 2) intervention coverage is responsive to policy action and, given the larger ARR associated with lower SEP, efforts can be productively focused on improving intervention coverage in this population group in order to reduce disparities.

Strengths and limitations

The use of a self-reported population health survey to define the study population provided both strengths and limitations in our community effectiveness calculations. One strength was the ability to calculate baseline risk of diabetes across key indicators of SEP using a population-based multivariate risk algorithm. These algorithms use individual data from population health surveys and are the most discriminating approach to estimate baseline risk.[6] The use of a population health survey also allowed flexibility in examining different SEP strata and target populations. Indeed, most components of community effectiveness could be varied for individual survey respondents, allowing a wide range of sensitivity analyses. We varied intervention efficacy based on age and BMI, but could have also varied it based on other attributes. Similarly, we varied coverage based on SEP strata, but it would have been straightforward to vary coverage on other respondent characteristics.

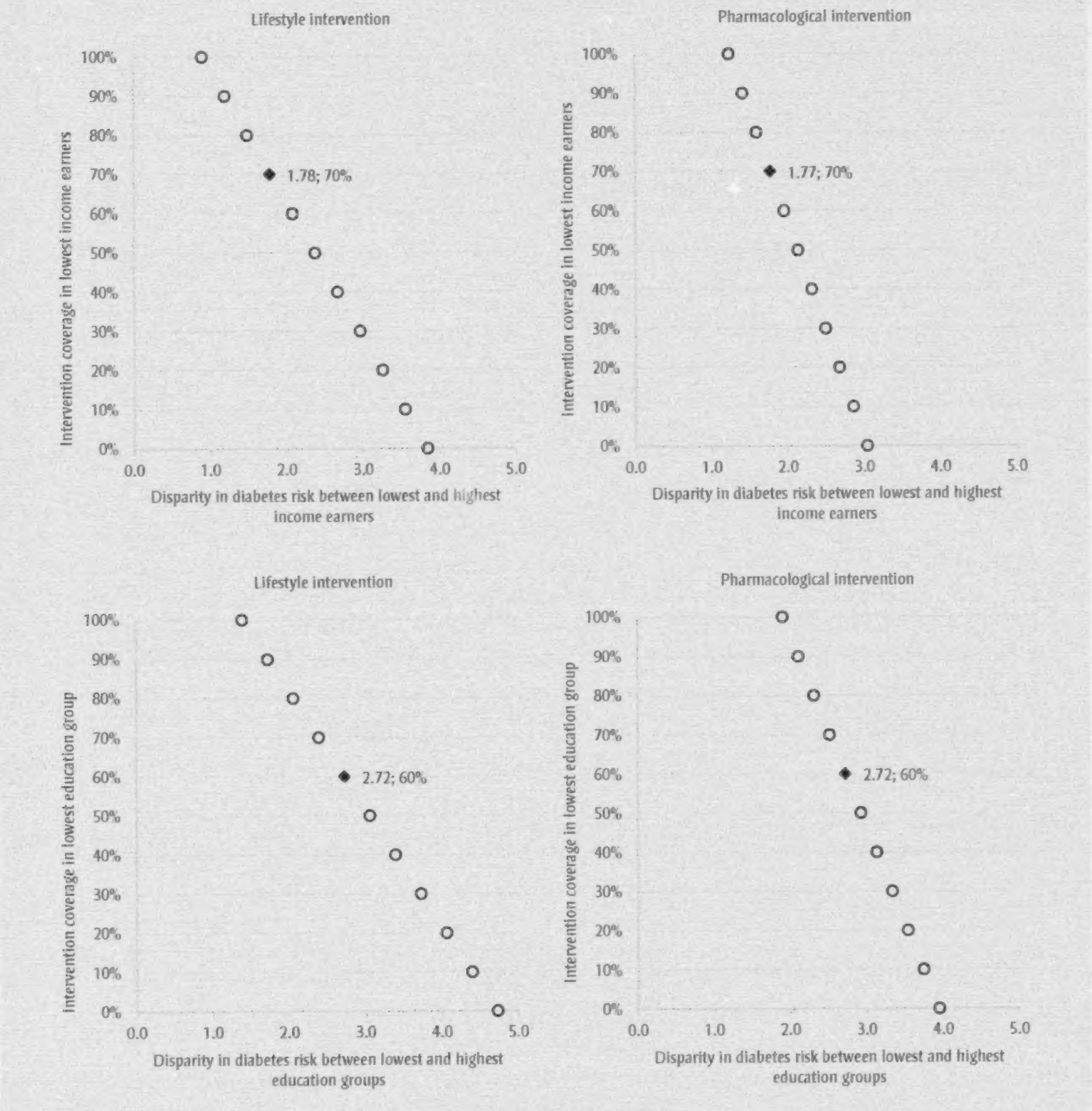
Our findings were based on the assumption that the relative benefit of lifestyle and pharmacological interventions for people at risk of diabetes was constant across SEP. Future applications of the modelling approach we have described would be strengthened by examining the effect of varying intervention effectiveness across SEP. However, there is some evidence to suggest diabetes prevention is equally efficacious—in relative terms—across SEP strata. For example, the Diabetes Prevention Program Research Group showed similar preventive benefit in all racial and ethnic groups in a study base of 27 centres across the United States.[8] The studies reviewed by Gillies et al.[7] were conducted in a wide range of community and ethnic settings worldwide with no heterogeneity identified. Second, lifestyle interventions have been shown to be comparatively effective, although with lower coverage, in low-income groups.[24] Finally, few studies and reviews have examined intervention efficacy differences across SEP strata. To address this important evidence gap, the Cochrane and Campbell Collaborations recently called for greater inclusion of equity in reviews and have provided a framework to facilitate the process.[25]

Conclusion

The community effectiveness of a preventive intervention can be calculated using a simple model that considers target population size, baseline risk of disease, intervention efficacy and intervention coverage. The potential for interventions to reduce inequities can be estimated when commu-

FIGURE 2

Estimating the impact of intervention coverage on the disparity in diabetes risk and identifying the equity tipping point for lifestyle and pharmacological interventions



Note: These scenarios assume 100% coverage in the highest socioeconomic group and varying coverage among the lowest socioeconomic group.

nity effectiveness is calculated for different socioeconomic strata. However, a current challenge is the lack of information on achievable levels of coverage and/or likely differences in target populations and intervention efficacy. Sensitivity analyses can be performed to estimate the equity tipping point, the setting where the intervention effect changes from reducing inequities to perversely increasing disparities in disease risk. Such sensitivity analyses can vary the expected coverage or other components of community effectiveness to examine their plausible influence and strengthen the evidence on the potential for reducing health inequities through individual-based prevention strategies.

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Cancer risk factors and screening in the off-reserve First Nations, Métis and non-Aboriginal populations of Ontario

D. R. Withrow, MSc (1, 2); A. Amartey, MPH (1); L. D. Marrett, PhD (1, 2)

This article has been peer reviewed.

Abstract

Introduction: This study describes the prevalence of smoking, obesity, sedentary behaviour/physical activity, fruit and vegetable consumption and alcohol use as well as the uptake of breast, cervical and colorectal cancer screening among First Nations and Métis adults in Ontario and compares these to that of the non-Aboriginal population.

Methods: We used the Canadian Community Health Survey (2007 to 2011 combined) to calculate prevalence estimates for the 3 ethnocultural populations.

Results: First Nations and Métis adults were significantly more likely than non-Aboriginal adults to self-report smoking and/or to be classified as obese. Alcohol use exceeding cancer prevention recommendations and inadequate fruit and vegetable consumption were more common in First Nations people than in the non-Aboriginal population. First Nations women were more likely to report having had a Fecal Occult Blood Test in the previous 2 years than non-Aboriginal women. No significant differences across the 3 ethnocultural groups were found for breast and cervical screening among women or colorectal screening among men.

Conclusion: Without intervention, we are likely to continue to see a significant burden of smoking- and obesity-related cancers in Ontario's Aboriginal population.

Keywords: cancer, chronic disease, American native continental ancestry group, risk factors, mass screening, indigenous population, First Nations, Métis, Ontario

Introduction

Cancer is one of the leading causes of death among Aboriginal people.[1] Historically, cancer was less common in Aboriginal people in Canada, but cancer incidence is increasing at a rate exceeding that of the non-Aboriginal population, for whom cancer rates have been relatively stable over the last 20 years.[2,3] Knowing the prevalence of cancer risk factors and the uptake of cancer screening in Aboriginal subpopulations is important to be able to support the development of Aboriginal-focused cancer control and prevention strategies.

Population-based health surveys are a common source of data to assess risk factor prevalence in the general population. However, their use for studying Aboriginal health has proved challenging. While several surveys in recent years have included ethnocultural variables to identify respondents as Aboriginal, national population-based health surveys typically sample a relatively small number of Aboriginal people. With health service delivery for Aboriginal peoples increasingly shifting toward provincial jurisdiction,[4] provincial health statistics for subpopulations are necessary. Stratifying national population-based surveys by province, however, further limits the number of Aboriginal respondents available. For example, although Ontario has the largest Aboriginal population in Canada, about 200 000 First Nations and 86 000 Métis,[5] the number of Aboriginal people sampled by national surveys such as the Canadian Community Health Survey (CCHS) remains low. The CCHS samples about 21 000 respondents from Ontario each year, of whom about 600 self-identify as Aboriginal, a number insufficient to produce interpretable and meaningful Ontario First Nations- and Métis-specific estimates for any single survey year.

To overcome the problem of small samples, our paper builds on recent work by Statistics Canada by pooling multiple survey years of the CCHS.[6] We have added to this work by including more recent data from 2011, by focusing specifically on cancer-related risk factors, by estimating the uptake of cancer screening modalities, and by considering the impact of sociodemographic factors. Specifically, our work aims to (1) measure the prevalence of smoking, obesity, physical activity/sedentariness, fruit and vegetable intake and alcohol use in Ontario First Nations and Métis and to compare these risk factors for cancer[7-12] with those in the non-Aboriginal population, and (2) measure the prevalence of up-to-date colorectal, breast and cervical screening in Ontario First Nations and Métis and compare these to screening rates in the non-Aboriginal population. In both instances, we have considered the impact of sociodemographic factors. With this analysis, we hope to highlight areas for action in Aboriginal cancer control and

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Author references:

1. Surveillance and Prevention, Prevention and Cancer Control, Cancer Care Ontario, Toronto, Ontario, Canada
2. Department of Epidemiology, Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada

Correspondence: Diana R. Withrow, Surveillance and Prevention, Prevention and Cancer Control, Cancer Care Ontario, 505 University Ave, Toronto, ON M5G 1X3; Tel.: 416-971-9800, ext. 3125; Fax: 416-971-6888; Email: diana.withrow@cancercare.on.ca

provide a baseline against which future measures of these constructs can be compared.

Methods

Data source

This study draws on data collected by Statistics Canada between 2007 and 2011 through the CCHS. The target population of this survey was people aged 12 years and older in the 10 provinces and territories excluding those living in institutions, in the Quebec health regions of Nunavik and Terres-Cries-de-la-Baie-James, or on reserve or in other Aboriginal settlements in the provinces. Survey respondents were sampled from the population at large using 3 sampling frames, with 99% of the sample selected using an area- or telephone-based sampling frame. About 1% of the sample was identified through random digit dialing. The survey was conducted with computer-assisted interviewing with an approximately equal number of respondents surveyed in person as by phone.[13]

For this report, we restricted the sample to adult respondents in the province of Ontario. Between 2007 and 2011, the response rate in Ontario varied from 68.7% to 73.6%.[13] To increase the number of First Nations and Métis responses eligible for analysis, the microdata files from all 5 annual releases of CCHS data from 2007 to 2011 were combined and prevalence estimates were calculated for all 5 years combined as per the methodology described by Statistics Canada.[14]

Measuring risk factors and screening

We calculated the prevalence of 6 risk factors and 3 screening modalities. Unless otherwise specified, risk factor analyses included respondents aged 18 years and over. Respondents with a missing or invalid response to a given question were excluded from the denominator of that indicator. Age limits and response cut-off points for each screening measure were based on Ontario guidelines for that screening modality.[15-17] For sedentary behaviour and breast and cervical screening, relevant questions were only posed in the 2007, 2008 and 2011 surveys.

The definitions of each indicator are described in more detail below.

- We defined the smoking indicator as the proportion of respondents aged 20 years and over who reported that they smoked daily or occasionally. A cut-off age of 20 years was used to be consistent with other Ontario public health indicators.[18]
- We defined the obesity indicator as the proportion of respondents who, based on self-reported height and weight, had a body mass index (BMI) of 30 kg/m^2 or more. Pregnant and lactating women were excluded.
- We defined the sedentary behaviour indicator as the proportion of respondents who spent at least 11 hours per week on a computer and/or at least 15 hours per week watching television outside of school or work.
- We defined the leisure time physical activity indicator as the proportion of respondents classified as either moderately active or active during leisure time in the previous 3 months, based on a daily estimated energy expenditure (EE) exceeding 1.5 kcal/kg/day. To determine EE, respondents were asked about the frequency and duration of different activities, such as swimming, ice-skating, volleyball, etc. EE was calculated by combining this information with the metabolic equivalent of the activity, which takes into account intensity of the activity.
- We defined the fruit and vegetable intake indicator as the proportion of respondents who consumed fruit or vegetables, excluding potatoes, at least 5 times per day based on an abridged food frequency questionnaire. Like the CCHS documentation, which uses times and servings interchangeably, we mainly use the term servings throughout this paper, but note that the CCHS asks respondents how many times they have eaten a given fruit or vegetable within the recall period.
- We defined the average daily alcohol consumption indicator as the proportion of female respondents who drank, on average, more than 1 drink per day and the proportion of male respondents who drank, on average, more than 2 drinks per day in the week preceding the interview. This cut-off was based on cancer prevention recommendations that suggest consuming no more than this amount.[19] Pregnant women were excluded.
- We defined the cervical cancer screening indicator as the proportion of women aged 21 to 69 years who reported having had a Pap smear test in the previous 3 years.
- We defined the breast cancer screening indicator as the proportion of women aged 50 to 74 years who reported having had a mammogram in the previous 2 years. To capture mammograms for the purposes of screening rather than as diagnostic investigations, we excluded those women who reported having had a mammogram because of a previously detected lump, follow-up of breast cancer treatment, breast problem or "other [non-screening] reason."
- We calculated 2 indicators for colorectal cancer screening. First, we measured the proportion of respondents aged 50 to 74 years who reported having had a Fecal Occult Blood Test (FOBT) in the previous 2 years. Second, we calculated the proportion of adults in that age range who had not had an FOBT in the previous 2 years, or a colonoscopy and/or sigmoidoscopy in the previous 10 years, and were accordingly due for colorectal cancer screening.

Aboriginality

From 2007 to 2010, all CCHS respondents were asked, "Are you an Aboriginal person, that is, North American Indian, Métis or Inuit?" If the respondent said yes, he or she would be asked to specify the subpopulation to which he or she belonged. In 2011, this question was only posed to those respondents who had previously reported that they were born in Canada, the United States, Germany or Greenland. To be consistent, we classified 2007 to 2010 respondents as First Nations and Métis only if they had also reported being born in one of these four countries.[20]

We used mutually exclusive ethnocultural categories despite that respondents could report multiple Aboriginal identities. For example, any respondent who replied that they were First Nations only or First Nations and Inuit was classified as First Nations. Any respondent who replied that they were Métis only or Métis and any other Aboriginal identity was classified as Métis. Due to small sample sizes, we did not generate Inuit-specific estimates in this report. Our definitions of First Nations and Métis are further illustrated in Table 1.

Statistical analysis

The CCHS has a multi-stage, complex sampling design. Sampling weights assigned by Statistics Canada are used to account for selection probability, non-response and non-coverage. For this report, weights were also adjusted to take into account the amalgamation of several survey cycles.[14] We used bootstrapping techniques to calculate the coefficient of variation (CV) and 95% confidence intervals (CIs). In accordance with Statistics Canada regulation, estimates with a CV ranging from 16.6% to 33.3% are flagged to be interpreted with caution. Those with a CV greater than 33.3% are suppressed because of extreme sampling variability.

Estimates were age-standardized to the age structure of the Ontario Aboriginal identity population in the 2006 Census using the age groups 20 to 24, 25 to 44, 45 to 64, and 65 years and over. For those indicators whose cut-off points for age did not line up with those provided by the census, age-standardization was to the nearest age group (e.g. 18- and 19-year olds were standardized to the 20- to 24-year age group).

We used logistic regression to generate odds ratios (ORs) of risk factor prevalence and uptake of screening in First Nations and Métis compared with the non-Aboriginal Ontario population. We present sex-specific age-adjusted ORs and ORs adjusted for age, income quintile, education and rural/urban place of residence as reported in the CCHS. CCHS survey year was controlled in both models. Estimates were considered statistically significantly different from the reference if the 95% CIs of the OR did not overlap with 1.00.

Results

Combining 5 years of Ontario CCHS data yielded 90 866 respondents aged 18 years and over for analysis, of whom 1468 identified as off-reserve First Nations and 990 as Métis. The demographic characteristics of respondents belonging to each ethnocultural group are summarized in Table 2. The First Nations and Métis populations were younger than the non-Aboriginal population, had less schooling and lower income, and were more likely to live in a rural setting rather than an urban one.

TABLE 1
Definitions of First Nations (off-reserve), Métis and non-Aboriginal identity based on Canadian Community Health Survey responses

	Aboriginal identity[a]	Subgroup identity[b]			
		Single	Multiple		
First Nations (off-reserve)	Yes	First Nations			
	Yes		First Nations		Inuit
Métis	Yes	Métis			
	Yes		First Nations	Métis	
	Yes			Métis	Inuit
	Yes		First Nations	Métis	Inuit
Non-Aboriginal	No	Born in any country			
	Yes	Born outside of Canada, USA, Germany, Greenland			

[a] Respondents were asked: "Are you an Aboriginal person, that is, North American Indian, Métis or Inuit?"

[b] Respondents were asked: "Are you North American Indian (First Nations)? ...Métis? ...Inuit (Inuk)?" and were permitted to provide multiple affirmative responses. Dark grey boxes are used because single and multiple identity responses are mutually exclusive.

Risk factors

Table 3 and Figures 1 and 2 show prevalence estimates of risk factors and screening uptake while Table 4 shows odds ratios. The most notable differences in risk factor prevalence between First Nations, Métis and non-Aboriginal people were related to smoking and obesity. Off-reserve First Nations and Métis men were more than twice as likely to report smoking than their non-Aboriginal peers (First Nations OR = 2.33, 95% CI: 1.79–3.02; Métis OR = 2.09, 95% CI: 1.54–2.83), with 44.9% (95% CI: 39.1–50.7) of First Nations men and 42.9% (95% CI: 36.1–49.6) of Métis men smoking compared with 26.2% (95% CI: 25.3–27.1) of non-Aboriginal men. Despite lower smoking prevalence in women, the disparity between ethnicities exceeded that in men. First Nations women were about 3.5 (OR = 3.56, 95% CI: 2.75–4.61) times more likely to smoke than non-Aboriginal women and Métis women were about 2.5 (OR: 2.47, 95% CI: 1.86–3.28) times more likely to smoke than non-Aboriginal women. Compared with non-Aboriginal people, First Nations and Métis were both about twice as likely to be classified as obese. Obesity rates ranged from 16.0% in non-Aboriginal women to 33.4% in First Nations men.

First Nations men and women were significantly less likely than non-Aboriginal people to consume at least 5 servings of fruit and vegetables daily (male OR = 0.72, 95% CI: 0.54–0.97; female OR = 0.64, 95% CI: 0.51–0.81), although this difference was not significant in men after accounting for sociodemographic differences. There were no significant differences in fruit and vegetable intake between Métis and non-Aboriginal men and women.

First Nations and Métis men were about 50% more likely than non-Aboriginal men to surpass the recommended daily limits of alcohol consumption for cancer prevention (First Nations OR = 1.50, 95% CI: 1.08–2.07; Métis OR 1.57, 95% CI: 1.06–2.31). This difference was no longer statistically significant in Métis after taking into account sociodemographic differences, however. There was a trend toward increased alcohol

TABLE 2
Sociodemographic characteristics of Ontario respondents to the CCHS, ≥ 18 years, by Aboriginal identity (off-reserve population), 2007–2011 CCHS combined data

Characteristics	Non-Aboriginal (N = 88 408)	First Nations (off-reserve) (n = 1 468)		Métis (n = 990)	
		%	p value[a]	%	p value[a]
Sex					
Male	48.8	48.1		46.0	
Female	51.2	51.9	.720	54.0	.295
Age group, years					
18–24	12.3	16.6		10.5	
25–44	36.0	41.5		46.5	
45–64	35.0	34.5		35.1	
≥ 65	16.7	7.4	< .001	8.0	< .001
Education					
Less than Secondary	12.8	22.3		21.6	
Secondary / Some post-secondary	26.3	30.2		28.8	
Post-secondary	61.0	47.5	< .001	49.6	< .001
Income quintiles					
1 (Lowest)	18.3	33.1		19.3	
2	19.7	18.6		24.1	
3	20.3	17.0		20.9	
4	20.5	18.0		18.8	
5 (Highest)	21.3	13.3	< .001	16.9	.097
Place of residence[b]					
Urban	89.5	81.1		78.4	
Rural	10.5	18.9	< .001	21.6	< .001

Source: Canadian Community Health Survey (2007–2011 combined), Statistics Canada.

Abbreviations: CA, Census Agglomeration; CCHS, Canadian Community Health Survey; CMA, Census Metropolitan Area.

[a] p values were generated through a χ^2 test for difference in proportions between the First Nations and the non-Aboriginal populations and the Métis and non-Aboriginal populations respectively.

[b] Urban place of residence includes respondents living in a CMA, a Tracted CA, or a Non-Tracted CA. Rural place of residence includes non-CMA and non-CA locations.

consumption in First Nations and Métis women relative to non-Aboriginal women, but a statistically significant difference between First Nations and non-Aboriginal women emerged only after accounting for sociodemographic characteristics. While controlling for sociodemographic characteristics occasionally changed the statistical significance of a finding, it did not appreciably affect our interpretation of the odds ratios overall.

Screening uptake

In women, there was no statistically significant difference in uptake of mammographic or cervical cancer screening between the 3 ethnocultural groups. Most women had undergone a Pap smear test in the previous 3 years (76.8% of First Nations, 72.3% of Métis and 78.0% of non-Aboriginal women). Fewer women, however, reported having had a mammogram in the previous 3 years, with fewer than 60% of First Nations and Métis women having done so, compared with nearly 70% of non-Aboriginal women.

About half of the respondents were due for colorectal cancer screening, having not had an FOBT in the previous 2 years or colonoscopy and/or sigmoidoscopy in the previous 10 years. Rates of underscreening were lower among women, and especially low (although the difference was not statistically significant) in First Nations women, among whom 38.8% were underscreened. This difference could be attributed to the apparent increased uptake of FOBT among First Nations women, who were almost twice as likely (OR = 1.78, 95% CI: 1.22–2.59) to have undergone the test compared with their non-Aboriginal peers.

Discussion

Analysis of the 2007 to 2011 CCHS revealed notable differences in the prevalence of certain cancer risk factors and uptake of cancer screening between Ontario's First Nations, Métis and non-Aboriginal populations.

Most notably, smoking and obesity were significantly more prevalent in First Nations and Métis, an observation that has been reported at national and provincial levels.[21-26] Data collected on First Nations reserves show a greater disparity, with on-reserve First Nations reporting higher rates of smoking and obesity than off-reserve populations.[25,26] Despite evidence suggesting decreasing rates of smoking and obesity in off-reserve Aboriginal populations between 2001 and 2008,[27] the prevalence of these 2 risk factors remains significantly higher than that in the general population. Much of the rapid increase in cancer within the Aboriginal population is attributed to the increasing incidence of lung and colorectal cancers,[27-29] both of which have been linked to tobacco smoking and colorectal cancer to obesity.[7,8,30] It is therefore imperative that interventions that reduce these negative risk factors within the Aboriginal population be a priority.

The analyses also showed lower prevalence of adequate fruit and vegetable intake and higher prevalence of alcohol consumption among First Nations compared with the non-Aboriginal population. Previous evidence has shown that, in addition to decreased fruit and vegetable consumption, off-reserve First Nations women had a higher average daily caloric intake, Aboriginal women ate fewer servings of grain, and Aboriginal men had fewer servings of dairy compared with the general population.[31] This is of concern as several studies have found a link between an unhealthy diet and increased risk of cancer.[10]

TABLE 3

Age-standardized prevalence of selected risk factors and cancer screening uptake for adult population (≥ 18 years unless otherwise specified), by Aboriginal identity, off-reserve population, Ontario, 2007–2011 CCHS combined data

	Males						Females					
	Non-Aboriginal		First Nations (off-reserve)		Métis		Non-Aboriginal		First Nations (off-reserve)		Métis	
Indicator	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI	%	95% CI
Risk/protective factors												
Daily or occasional smoker	26.2	25.3–27.1	44.9	39.1–50.7	42.9	36.1–49.6	17.8	17.2–18.4	43.2	37.1–49.4	35.1	28.7–41.5
Obese	18.9	18.2–19.6	33.4	27.2–39.5	27.8	21.3–34.4	16.0	15.4–16.6	25.8	21.3–30.4	25.6	17.6–33.6
Sedentary[a]	45.0	43.8–46.2	51.7	43.0–60.4	43.4	35.5–51.4	39.6	38.6–40.7	50.3	43.5–57.1	40.2	32.5–47.9
Physically Active	52.4	51.5–53.4	58.9	52.9–64.9	53.2	46.7–59.7	46.6	45.8–47.4	50.1	44.5–55.7	51.4	43.6–59.1
≥ 5 servings of fruit and vegetables / day	29.4	28.6–30.1	23.5	18.3–28.7	23.7	18.1–29.2	42.6	41.8–43.4	31.4	26.4–36.3	35.8	28.9–42.7
> 1 or 2 alcoholic drinks/day[b]	9.8	9.3–10.3	14.3	10.4–18.1	16.4	11.5–21.3	8.6	8.1–9.1	10.6	7.8–13.5	10.2[E]	6.2–14.2
Screening uptake												
Mammogram in the previous 2 years[a]		—		—		—	67.9	56.8–69.9	59.7	47.1–72.3	59.2	45.6–72.7
Cervical test in the previous 3 years[a]		—		—		—	78.0	77.0–79.0	76.8	71.7–81.8	72.3	63.9–80.8
FOBT in the previous 2 years	25.5[E]	23.8–27.3	28.5[E]	15.7–41.3	23.6	15.7–31.3	28.2	26.7–29.7	39.6	29.8–49.3	22.4	15.2–29.6
Underscreened for colorectal cancer[c]	49.1	47.2–51.1	52.3	39.9–64.7	53.4	40.5–66.2	45.1	43.4–46.8	38.8	29.0–48.5	46.0	34.2–57.7

Source: Canadian Community Health Survey (2007–2011 combined), Statistics Canada.

Abbreviations: CCHS, Canadian Community Health Survey; CI, confidence interval; FOBT, Fecal Occult Blood Test.

Notes: All estimates are age-standardized to the 2006 Ontario Aboriginal identity population. Estimates represent the adult population (≥ 18 years) with the exception of the following indicators: "current smoking" includes population ≥ 20 years; "alcohol consumption" includes population ≥ 19 years; "FOBT," "underscreened for colorectal cancer" and "mammogram" include population 50–74 years; "Pap smear test" includes population 21–69 years.

[a] Indicator not included in the 2009 and 2010 CCHS surveys. Estimates for these indicators represent 2007, 2008 and 2011 CCHS combined data.

[b] > 1 drink/day on average in women; > 2 drinks/day on average in men.

[c] Represents the percentage of respondents who have not had an FOBT in the previous 2 years nor a colonoscopy and/or sigmoidoscopy in the previous 10 years.

[E] Estimate should be interpreted with caution. Coefficient of variation is between 16.6% and 33.29%.

We are not aware of any study of Aboriginal people in Canada that used an indicator of alcohol consumption based on cancer prevention recommendations similar to the one we used, although increased frequency of binge drinking in Ontario's First Nations and Métis populations has been reported.[5,23] With earlier data showing a lower prevalence of heavy alcohol use among Aboriginal people compared with the general population,[22] our findings along with other more recent data[6,24] suggest an increasing pattern of risky drinking within the Aboriginal population over time.

No significant differences in breast and cervical cancer screening use were found across the 3 ethnocultural groups. There was a trend towards lower rates of mammography use in First Nations and Métis women, but notably, none of the ethnocultural groups reached the national target of 70% coverage.[32] Data on mammography uptake by Aboriginal women is limited, but a Manitoba-based study reported significantly lower uptake in on-reserve First Nations women compared with women in rural areas.[33] In addition, an earlier study suggested that members of the visible minorities in Canada were less likely than whites to report having had a mammogram.[34]

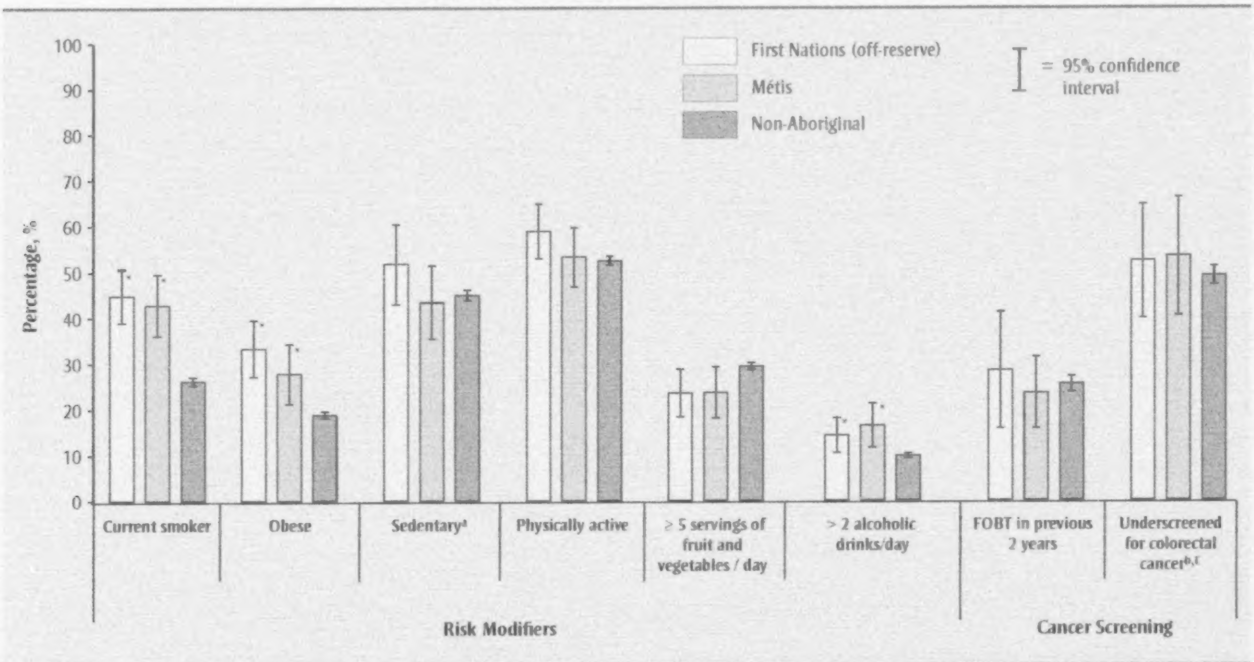
Consistent with earlier research, our study found that 70% of women reported having had a Pap smear test in the previous 3 years.[34] Despite adequate screening, however, the burden of cervical cancer among Aboriginal women is disproportionately high, suggesting that more or different preventive actions may be warranted.[35]

Compared with non-Aboriginal women, First Nations women were significantly more likely to report having had an FOBT in the previous 2 years and were less likely to be underscreened for colorectal cancer after taking into account colonoscopy and sigmoidoscopy. The 2 colorectal cancer screening indicators interpreted together suggest a stronger propensity for FOBT uptake (as opposed to a colonoscopy or sigmoidoscopy) in the First Nations population compared with both the Métis and non-Aboriginal populations. This uptake could be attributed, at least in part, to Cancer Care Ontario's 2008/09 implementation of an educational initiative to raise awareness about colorectal cancer, prevention and FOBT screening in First Nations communities.[36]

Social factors are particularly important to consider when studying Aboriginal health. Aboriginal people in Canada are more likely to live in poverty, report lower

FIGURE 1

Prevalence of selected risk factors and up-to-date colorectal screening uptake for adult male population, ≥ 18 years, by Aboriginal identity, off-reserve population, Ontario, 2007–2011 CCHS combined data



Source: Canadian Community Health Survey (2007–2011 combined), Statistics Canada.

Abbreviations: CCHS, Canadian Community Health Survey; FOBT, Fecal Occult Blood Test.

Notes: All estimates are age-standardized to the 2006 Ontario Aboriginal identity population. Estimates represent the adult population (≥ 18 years) with the exception of the following indicators: "current smoking" includes population ≥ 20 years; "alcohol consumption" includes population ≥ 19 years; "FOBT" and "underscreened for colorectal cancer" include population aged 50–74 years.

[a] Indicator not included in the 2009 and 2010 CCHS surveys. Estimates for sedentary behaviour represent 2007, 2008, and 2011 CCHS combined data.

[b] Represents the percentage of respondents who had not had either of an FOBT in the previous 2 years or a colonoscopy and/or sigmoidoscopy in the previous 10 years.

[c] Estimates for First Nations and Métis should be interpreted with caution. Coefficient of variation is between 16.6% and 33.29%.

[*] Based on non-overlapping confidence intervals, estimate is significantly different from non-Aboriginal estimate for the corresponding risk factor.

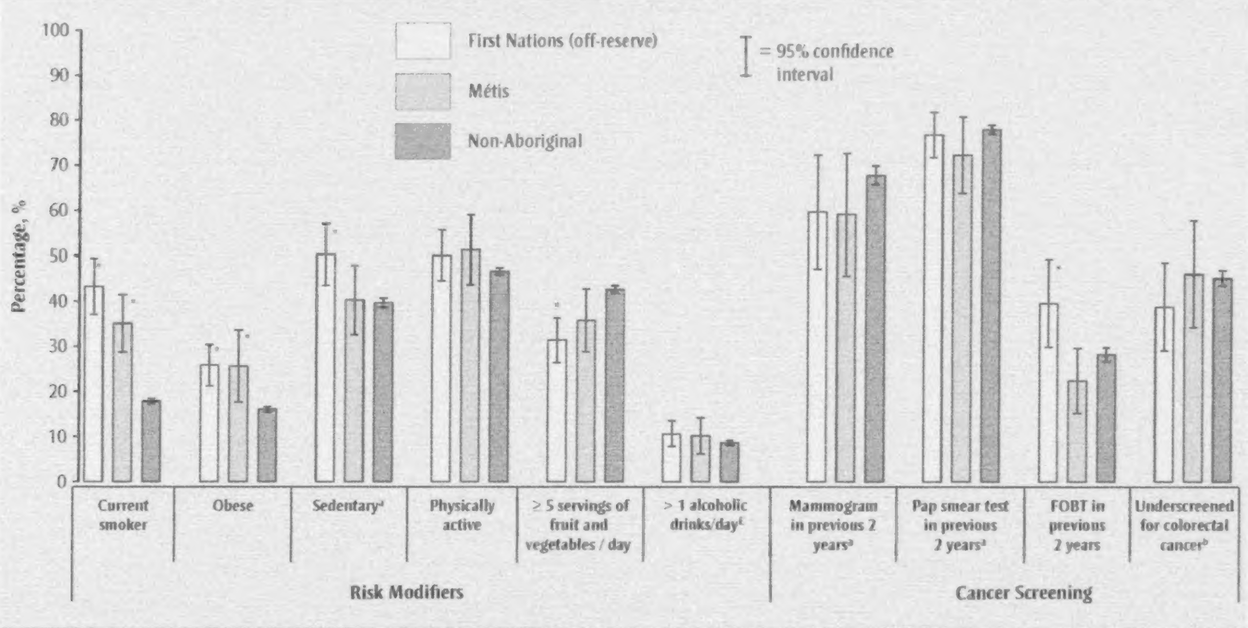
household income, and experience lower educational achievement compared with non-Aboriginal people.[21,23,37] In addition, First Nations and Métis are more likely to live in rural areas and rural residence has been associated with difficulty accessing health services and increased likelihood of smoking, excess weight and poor self-rated health.[38] Nevertheless, we explored the impact of income, education and rural/urban status and found very little change in the likelihood of reporting risk factors and screening uptake in the Aboriginal population compared with the non-Aboriginal population after taking these into account. This suggests the robustness of ethnicity as a determinant of health-related lifestyle factors in the First Nations and Métis.

Strengths and limitations

Although ethnicity, socioeconomic status and place of residence are known determinants of common chronic disease risk factors, we were unable to consider other important determinants of health and disease in this study. For example, more distal factors such as the health care system, racism and social capital have important indirect effects on Aboriginal health but these factors cannot be taken into account using CCHS data.[23,39] In addition, we were only able to examine the prevalence of each risk factor individually and did not assess the relationships between them. For example, we estimated the prevalence of physical activity, diet and obesity, and though we know that physical activity and diet are strong determinants of obesity,[40] we did not explore their relationship in this study. This gap presents an opportunity for researchers to consider multiple related risk factors and chronic diseases in Aboriginal and non-Aboriginal populations through causal modelling.

The exclusion of individuals living on-reserve from the CCHS is another limitation of this work. Evidence from the First Nations Regional Health Survey, a survey of on-reserve First Nations, suggests that in addition to a higher prevalence of smoking and obesity in on-reserve communities, physical activity appears to be

FIGURE 2
Prevalence of selected risk factors and up-to-date mammogram, cervical and colorectal screening uptake for adult female population, ≥ 18 years, by Aboriginal identity, off-reserve population, Ontario, 2[illegible]-2011 CCHS combined data



Source: Canadian Community Health Survey (2007–2011 combined), Statistics Canada.

Abbreviations: CCHS, Canadian Community Health Survey; FOBT, Fecal Occult Blood Test.

Notes: All estimates are age-standardized to the 2006 Ontario Aboriginal identity population. Estimates represent the adult population (≥ 18 years) with the exception of the following indicators: "current smoking" includes population ≥ 20 years; "alcohol consumption" includes population ≥ 19 years; "FOBT," "underscreened for colorectal cancer" and "mammogram" include population aged 50–74; "Pap smear test" includes population aged 21–69 years.

[a] Not included in the 2009 and 2010 CCHS surveys. Estimates for these indicators represent 2007, 2008 and 2011 CCHS combined data.

[b] Represents the percentage of respondents who have not had either of an FOBT in the previous 2 years or a colonoscopy and/or sigmoidoscopy in the previous 10 years.

[E] Estimate for Métis should be interpreted with caution. Coefficient of variation is between 16.6% and 33.29%.

[*] Based on non-overlapping confidence intervals, estimate is significantly different from non-Aboriginal estimate for the corresponding risk factor.

lower and cervical and breast cancer screening rates similar to our findings.[26]

By pooling responses from 5 CCHS, we were able to produce reportable prevalence estimates specific to Ontario First Nations and Métis, a strength of this work. The cost of this approach, however, is that the estimates represent an average prevalence over time rather than the most recent health status of the populations.

Finally, because of the self-reported nature of the survey, our results may be subject to social desirability bias whereby survey respondents tend to under-report behaviours that are socially undesirable and over-report those considered desirable. Arguably, this effect would be similar across cultural groups and would not significantly affect the relative prevalence of any risk factor.

Despite these limitations, the analyses we present in this study show that the CCHS can provide risk factor estimates for Ontario's off-reserve First Nations, Métis and non-Aboriginal population with consistent indicators across populations. Further, by assessing specific cancer-related risk factors such as sedentary behaviour, cancer screening uptake and alcohol consumption measured in relation to cancer prevention guidelines, this paper provides new evidence on the health status of Ontario's First Nations and Métis population, specifically as it relates to cancer risk.

Conclusion

Estimating the prevalence of risk factors and uptake of cancer screening in the First Nations and Métis is essential for the planning and provision of primary and secondary prevention services to this population. To monitor trends and identify targets for intervention, analyses such as this should be repeated over time. The increased prevalence of chronic disease risk factors among First Nations and Métis reported here supports provincial recommendations that culturally appropriate and specific actions be taken to address these factors to reduce the burden of cancer in particular and chronic disease more generally in this and future generations.[41]

TABLE 4
Adjusted odds ratios comparing First Nations and Métis adults with non-Aboriginal adults (≥ 18 years) for selected risk factors and uptake of cancer screening, Ontario, 2007–2011 CCHS combined data

Indicator	Males								Females							
	First Nations				Métis				First Nations				Métis			
	Model A[a]		Model B[b]		Model A[a]		Model B[b]		Model A[a]		Model B[b]		Model A[a]		Model B[b]	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Risk/protective factors																
Daily or occasional smoker	2.33	1.79–3.02	1.93	1.49–2.51	2.09	1.54–2.83	1.76	1.30–2.39	3.56	2.75–4.61	3.07	2.38–3.96	2.47	1.86–3.28	2.26	1.68–3.04
Obese	2.23	1.61–3.09	2.19	1.57–3.07	1.77	1.25–2.50	1.68	1.18–2.39	1.84	1.45–2.33	1.69	1.33–2.15	1.83	1.19–2.81	1.71	1.11–2.63
Sedentary[c]	1.15	0.79–1.68	1.09	0.75–1.59	0.92	0.62–1.36	0.92	0.63–1.36	1.40	1.05–1.85	1.29	0.97–1.72	1.07	0.74–1.54	1.06	0.73–1.53
Physically active	1.27	0.99–1.64	1.44	1.10–1.88	0.95	0.72–1.26	1.01	0.78–1.32	1.13	0.90–1.42	1.32	1.06–1.66	1.18	0.87–1.61	1.26	0.92–1.72
≥ 5 servings of fruit and vegetables / day	0.72	0.54–0.97	0.76	0.57–1.03	0.77	0.56–1.07	0.84	0.61–1.16	0.64	0.51–0.81	0.70	0.55–0.89	0.76	0.55–1.03	0.78	0.58–1.06
> 1 or 2 alcoholic drinks/day[d]	1.50	1.08–2.07	1.53	1.10–2.14	1.57	1.06–2.31	1.47	0.98–2.21	1.26	0.93–1.71	1.46	1.07–2.00	1.17	0.76–1.80	1.25	0.82–1.91
Screening uptake																
Mammogram in the previous 2 years[c]	—		—		—		—		0.68	0.41–1.11	0.83	0.52–1.34	0.84	0.47–1.49	0.89	0.51–1.56
Cervical test in the previous 2 years[c]	—		—		—		—		0.93	0.67–1.28	1.13	0.83–1.53	0.72	0.48–1.09	0.79	0.51–1.22
FOBT in the previous 2 years	0.98	0.58–1.66	1.04	0.62–1.76	1.10	0.65–1.87	1.19	0.70–2.01	1.78	1.22–2.59	1.83	1.25–2.67	0.91	0.50–1.65	0.93	0.52–1.66
Overdue colorectal screening[e]	1.17	0.76–1.80	0.99	0.65–1.51	1.12	0.69–1.82	0.94	0.58–1.55	0.75	0.52–1.10	0.69	0.47–1.01	1.04	0.65–1.66	0.99	0.63–1.56

Source: Canadian Community Health Survey, 2007–2011 (combined data), Statistics Canada.

Abbreviations: CCHS, Canadian Community Health Survey; CI, confidence interval; FOBT, Fecal Occult Blood Test; OR, Odds ratio.

[a] Model A is adjusted for age and survey year.

[b] Model B is adjusted for age, education, income quintile, urban vs. rural residence and survey year.

[c] Sedentary behaviour, mammography and cervical (Pap smear) test indicators were not measured in the 2009 and 2010 CCHS surveys. Estimates for these indicators represent 2007, 2008 and 2011 CCHS combined data.

[d] > 1/day on average in women; > 2/day on average in men.

[e] Represents the percentage of respondents who have not had an FOBT in the previous 2 years nor a colonoscopy and/or sigmoidoscopy in the previous 10 years.

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Are Canadian youth still exposed to second-hand smoke in homes and in cars?

A. Barisic, MPH (1); S. T. Leatherdale, PhD (2); R. Burkhalter, MMath (3); R. Ahmed, PhD (4)

This article has been peer reviewed.

Abstract

Introduction: The objective of this manuscript is to examine the prevalence of youth exposed to second-hand smoke (SHS) in homes and cars, changes in SHS exposure over time, and factors associated with beliefs youth hold regarding SHS exposure among a nationally representative sample of Canadian youth.

Methods: Descriptive analysis of SHS exposure in homes and cars was conducted using data from the Canadian Youth Smoking Survey (2004, 2006 and 2008). Logistic regression was conducted to examine factors associated with beliefs youth had about SHS exposure in 2008.

Results: In 2008, 21.5% of youth reported being exposed to SHS in their home on a daily or almost daily basis, while 27.3% reported being exposed to SHS while riding in a car at least once in the previous week. Between 2004 and 2008, the prevalence of daily SHS exposure in the home and cars decreased by 4.7% and 18.0% respectively.

Conclusion: Despite reductions in SHS exposure over time, a substantial number of Canadian youth continue to be exposed to SHS in homes and cars. Further effort is required to implement and evaluate policies designed to protect youth from SHS.

Keywords: youth, tobacco smoke pollution, prevention, car/vehicle, home/household

Introduction

Second-hand smoke (SHS) refers to the mixture of contaminants released from a burning cigarette from both the side stream smoke of the burning tobacco and the smoke that is exhaled into the air.[1] The adverse health effects associated with SHS have been extensively documented; they include an increased risk of cardiovascular disease and several cancers.[2] Of particular concern, however, is the emerging evidence that children are especially vulnerable to the negative health effects associated with SHS exposure.[2] Children have less developed immune systems, breathe more rapidly and, as a consequence of their small size, absorb more pollutants.[3] Accordingly, SHS exposure in youth has been linked to an increased risk of lower respiratory tract infections such as bronchitis and pneumonia, upper respiratory tract irritation, asthma, fluid in the middle ear, sudden infant death syndrome and decreased lung function.[1,4-6] Further, SHS exposure among youth has been linked to increased days of restricted activity, bed confinement and school absence.[7] There is even evidence suggesting that youth who are exposed to SHS are themselves more likely to become smokers.[8]

Despite evidence demonstrating the dangers of SHS exposure in vehicles,[9] using 2004 YSS data, Leatherdale and Ahmed[10] showed that 26.3% of Canadian youth were exposed to SHS while travelling in a vehicle at least once in the previous week. Similarly, 23.1% were exposed to SHS in their home every day, despite that the vast majority of youth reported believing that smoking should be prohibited in vehicles and in homes when children are present.[10] This disparity demonstrates that youth may be unable to prevent or limit their exposure to SHS in some contexts.

The purpose of this study is to examine (1) the frequency with which youth are exposed to smoking in their homes and cars, (2) the beliefs youth hold about smoking around children in these environments, (3) changes in prevalence of SHS exposure in these environments and (4) changes in beliefs about smoking between 2004 and 2008.

Methods

This study used nationally representative data collected as part of the 2004, 2006 and 2008 waves of the Canadian Youth Smoking Survey (YSS). Detailed information on the sample design, methods and survey rates for each wave of the YSS are available in print[11-13] and online (www.yss.uwaterloo.ca). In brief, the target populations for all three waves consisted of all young Canadian residents in the appropriate grades attending public and private schools in 10 Canadian provinces; residents of Yukon, Nunavut and the Northwest Territories were excluded from the target populations, as were youth living in institutions or on First Nation reserves and those

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Author references:

1. Prevention & Cancer Control, Cancer Care Ontario, Toronto, Ontario, Canada
2. School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, Canada
3. Propel Centre for Population Health Impact, University of Waterloo and the Canadian Cancer Society, Waterloo, Ontario, Canada
4. Epidemiology and Cancer Registry, Cancer Care Manitoba, Winnipeg, Manitoba, Canada

Correspondence: Scott T. Leatherdale, School of Public Health and Health Systems, University of Waterloo, 200 University Ave West, BMH 1038, Waterloo, ON N2L 3G1; Tel.: 519-888-4567 ext. 37812; Email: sleather@uwaterloo.ca

attending special schools or schools on military bases. Data were collected using a 30- to 40-minute classroom-based survey of a representative sample of schools and students. The main design difference across the three waves of YSS is the grades sampled: the 2004 YSS sampled students in grades 5 to 9, the 2006 YSS sampled students in grades 5 to 12 and the 2008 YSS sampled students in grades 6 to 12. In this report, we used data from respondents in grades 6 to 9 for the analyses examining changes in the prevalence of exposure to SHS in homes and in cars over time (2004, n = 23 362; 2006, n = 33 955; 2008, n = 31 249) and data from the full sample of 2008 YSS respondents (grades 6–12; n = 51 922) for the predictive modeling.

Each wave of the YSS collected information on SHS exposure in homes and in cars, beliefs about smoking in these environments, smoking behaviour, demographic characteristics and spending money. The measures used are consistent across YSS waves and other literature.[10,14] Beliefs about smoking were assessed by asking, "Should smoking be allowed around kids at home?" ("yes" / "no" / "I don't know") and "Should smoking be allowed around kids in cars?" ("yes" / "no" / "I don't know"). Respondents were asked "What are the rules about smoking in your home?" ("no one is allowed to smoke in my home" / "only special guests are allowed to smoke in my home" / "people are allowed to smoke only in certain areas in my home" / "people are allowed to smoke anywhere in my home"), "Excluding yourself, how many people smoke inside your home every day or almost every day?" ("none" / "1 person" / "2 people" / "3 or more people") and "During the past 7 days, on how many days did you ride in a car with someone who was smoking cigarettes?" ("0 days" / "1 or 2 days" / "3 or 4 days" / "5 or 6 days" / "all 7 days").

Analyses

Using the 2008 data from respondents in grades 6 to 12, we examined descriptive analyses of SHS exposure, beliefs about smoking, smoking status and demographic characteristics by sex. For the descriptive statistics, we used survey weights to adjust for non-response between provinces and groups, thereby minimizing any bias in the analyses caused by differential response rates across regions or groups. Generalized linear mixed models (using PROC GLIMMIX in SAS 9.2 [SAS Institute Inc., Cary, NC, US]) were used with the unweighted data to test whether being exposed to smoking at home or in the car was associated with the beliefs youth have about smoking around youth in either the home or the car, after controlling for sociodemographic variables (sex, smoking status, parental smoking and rules about smoking in the home) and adjusting for clustering within schools.

Results

Descriptive statistics for youth in grades 6 to 9 by year of data collection (2004, 2006 and 2008) are shown in Table 1. Descriptive statistics for youth in grades 6 to 12 by sex for 2008 are shown in Table 2. Figure 1 shows changes in the prevalence of youth reporting that they live in a smoke-free home by region, while Figure 2 shows changes in the prevalence

TABLE 1
Descriptive statistics for Canadian youth in grades 6–9, by year of data collection, Canada

	2004 (n = 1 622 900) %[a]	2006 (n = 1 662 300) %[a]	2008 (n = 1 610 300) %[a]	% Change 2004–2006 %	 2006–2008 %	 2004–2008 %
Rules about smoking in the home						
No one is allowed to smoke in my home	63.7	69.3	72.2	8.8[*]	4.2[*]	13.3[*]
Only special guests are allowed to smoke in my home	9.0	6.7	4.6	−25.6[*]	−31.3[*]	−48.9[*]
People are allowed to only smoke in certain areas in my home	14.8	14.1	14.8	−4.7[*]	5.0[*]	0.0
People are allowed to smoke anywhere in my home	12.4	9.9	8.4	−20.2[*]	−15.2[*]	−32.3[*]
Number of people who smoke inside the home every day or almost every day						
0	76.6	77.6	77.7	1.3[*]	0.1	1.4[*]
≥ 1	23.4	22.4	22.3	−4.3[*]	−0.4	−4.7[*]
Should smoking be allowed around kids at home						
No	97.0	96.1	95.7	−0.9[*]	−0.4[*]	−1.3[*]
Yes	3.0	3.9	4.3	30.0[*]	10.3[*]	43.3[*]
Number of days riding in a car with someone who was smoking cigarettes in the past 7 days						
0	72.2	74.1	77.2	2.6[*]	4.2[*]	6.9[*]
1–7	27.8	25.9	22.8	−6.8[*]	−12.0[*]	−18.0[*]
Should smoking be allowed around kids in cars						
No	96.8	96.1	95.7	−0.7[*]	0.4[*]	−1.1[*]
Yes	3.2	3.9	4.3	21.9[*]	10.3[*]	34.4[*]

[a] Weighted population estimate.

[*] Statistically significant difference, $p < .05$.

TABLE 2
Descriptive statistics for Canadian youth in grades 6–12, by sex, 2008, Canada

	Male (n = 1 460 300) %[a]	Female (n = 1 388 100) %[a]	Total (n = 2 848 500) %[a]
Grade			
6	13.1	13.6	13.3
7	13.8	14.2	14.0
8	14.3	14.5	14.4
9	14.9	14.8	14.8
10	15.5	14.8	15.2
11	14.9	14.7	14.8
12	13.6	13.4	13.5
Youth smoking status			
Never smoker	90.1	92.5	91.3
Current smoker	8.9	6.4	7.7
Former smoker	0.9	1.1	1.0
Parental smoking status			
No parent(s) smoke	56.1	57.0	56.5
At least 1 parent smokes	43.9	43.0	43.5
Region			
Atlantic Canada[b]	6.7	7.2	6.9
Quebec	19.3	19.4	19.4
Ontario	41.4	40.5	40.9
Prairies[c]	18.8	19.1	18.9
British Columbia	13.8	13.9	13.9
Rules about smoking in the home			
No one is allowed to smoke in my home	73.3	73.6	73.4
Only special guests are allowed to smoke in my home	4.4	4.5	4.5
People are allowed to only smoke in certain areas in my home	13.7	14.1	13.9
People are allowed to smoke anywhere in my home	8.6	7.8	8.2
Number of people who smoke inside the home every day or almost every day			
0	78.3	78.7	78.5
≥ 1	21.7	21.3	21.5
Should smoking be allowed around kids at home?			
No	93.2	97.2	95.2
Yes	6.8	2.8	4.8
Number of days riding in a car with someone who was smoking cigarettes in the past 7 days			
0	73.0	72.4	72.7
1–7	27.0	27.6	27.3
Should smoking be allowed around kids in cars?			
No	93.2	97.2	95.2
Yes	6.8	2.8	4.8

[a] Weighted population estimate.

[b] New Brunswick, Prince Edward Island, Nova Scotia, Newfoundland and Labrador.

[c] Alberta, Saskatchewan, Manitoba.

of youth reporting that they were exposed to smoking while riding in car in the previous 7 days, also by region. Figure 3 shows the changes in prevalence of exposure to smoking in homes and cars over time by sex and Figure 4 shows the prevalence of exposure to smoking and the beliefs about exposure held by students in grades 6 to 12 in 2008.

Exposure to smoking in the home

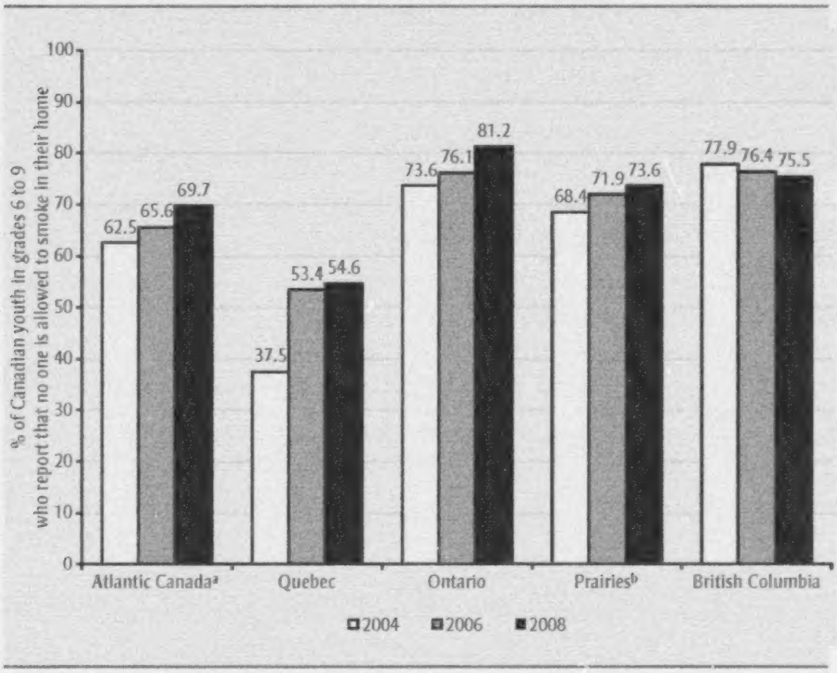
In 2008, about one-fifth (21.5%; n = 605 300) of Canadian youth in grades 6 to 12 were exposed to someone smoking in the home on a daily or almost daily basis, with rates of exposure similar in both male and female students (see Table 2). Moreover, 26.6% (n = 743 200) of youth reported living in a home where smoking is not completely restricted, with similar rates among male and female students. However, rates did vary by province ($\chi^2 = 2959.6$; $df = 12$; $p < .0001$). Ontario had the highest percentage of youth living in a home where respondents reported smoking is completely restricted (80.0%), while Quebec had the lowest percentage of smoke-free homes (56.1%; data not shown).

Between 2004 and 2008, the prevalence of youth in grades 6 to 9 reporting that no one is allowed to smoke in the home increased by 13.3% (Table 1). In addition, the prevalence of youth reporting that people are allowed to smoke anywhere in the home decreased by 32.3%. However, the prevalence of youth reporting being exposed to SHS inside the home on a daily or almost daily basis decreased by only 4.7%. Further, this decrease was only observed among female youth, with the prevalence increasing among male youth. For all provinces, except British Columbia, there was an increase in the prevalence of youth who reported no exposure to SHS in the home over time (Figure 1).

Exposure to smoking in cars

In 2008, over one-quarter (27.3%; n = 716 500) of youth in grades 6 to 12 had ridden in a car within the previous 7 days with someone who was smoking; male and female youth reporting similar rates of exposure. However, rates varied across provinces ($\chi^2 = 1138.1$; $df = 4$;

FIGURE 1
Changes in the prevalence of youth in grades 6 to 9 reporting that they live in a home where no one is allowed to smoke inside, by region of Canada, 2004, 2006, 2008



Source: 2004, 2006, 2008 Canadian Youth Smoking Surveys.[11,12,13]

[a] New Brunswick, Prince Edward Island, Nova Scotia, Newfoundland and Labrador.

[b] Alberta, Saskatchewan, Manitoba.

p < .0001), with the prevalence lowest in Ontario (20.1%) and highest in Quebec (37.5%; data not shown).

The prevalence of youth in grades 6 to 9 reporting being exposed to SHS in cars decreased by 18.0% between 2004 and 2008 (Table 1), as well as across all provinces except Quebec and British Columbia (Figure 2).

Beliefs about smoking at home

In 2008, the majority (95.2%; n = 2 473 900) of youth in grades 6 to 12 felt that smoking should not be permitted around children at home (Table 2). This belief was more commonly held by female students (97.2%) than by male students (93.2%) (χ^2 = 420.4; df = 1; p < .0001). Such beliefs about smoking in the home also varied across provinces (χ^2 = 127.8; df = 4; p < .0001), being most common among youth living in Ontario (96.3%) and least common among those living in Quebec (93.4%; data not shown).

For both sexes combined, the prevalence of youth in grades 6 to 9 who felt smoking should not be permitted around children at home decreased slightly by 1.3% between 2004 and 2008.

Beliefs about smoking in cars

In 2008, the majority (95.2%; n = 2 484 900) of youth in grades 6 to 12 felt smoking should not be permitted around children in cars (Table 2). This belief was more commonly held by female students (97.2%) than by male students (93.2%) (χ^2 = 419.5; df = 1; p < .0001) and also varied across provinces (χ^2 = 133.5; df = 4; p < .0001), being the strongest among youth living in Ontario (96.4%) and the weakest among youth living in Quebec (93.5%; data not shown).

For both sexes combined, the prevalence of youth in grades 6 to 9 who felt smoking should not be permitted around children in cars decreased by 1.1% between 2004 and 2008.

Factors associated with beliefs about smoking in the home

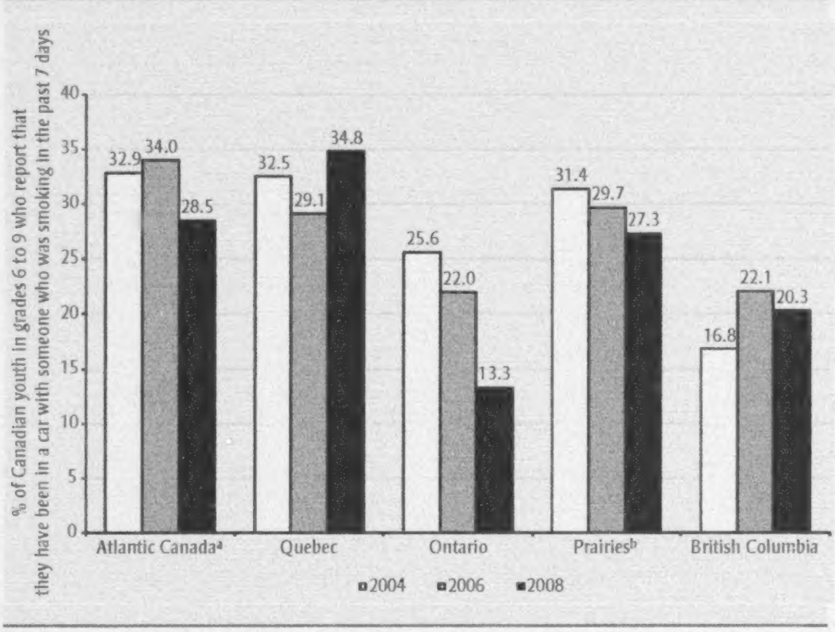
In comparison to their female counterparts, male youth in grades 6 to 12 in 2008 were more likely to report that smoking should not be permitted around children in the home (odds ratio [OR] = 2.43; 95% confidence interval [CI]: 2.20–2.69; Table 3). In comparison to current smokers, both former (OR = 1.82; 95% CI: 1.23–2.71) and never smokers (OR = 4.26; 95% CI: 3.78–4.79) were more likely to report smoking should not be permitted around children in the home. In comparison to youth who live in a home where smoking is completely restricted, youth who reported living in a home where smoking is allowed are also more likely to report smoking should not be permitted around children in the home (OR = 1.71; 95% CI: 1.50–1.96). Similarly, in comparison to youth who reported no SHS exposure in the car in the previous week, youth who reported riding in a car in the previous week with someone who was smoking were more likely to report that smoking should not be permitted around children in the home (OR = 2.04; 95% CI: 1.81–2.29).

Factors associated with beliefs about smoking in cars

In comparison to their female counterparts, male youth in grades 6 to 12 in 2008 were more likely to report that smoking around children should not be permitted in cars (OR = 2.58; 95% CI: 2.33–2.85). In comparison to current smokers, both former (OR = 2.02; 95% CI: 1.39–2.94) and never smokers (OR = 4.14; 95% CI: 3.68–4.65) were more likely to report that smoking around children should not be permitted in cars. In comparison to youth who live in a home where smoking is completely restricted, youth who reported living in a home where smoking is allowed were more likely to report that smoking around children should not be permitted in cars (OR = 1.59; 95% CI: 1.39–1.82). Similarly, in comparison to youth who reported no SHS exposure in the car in the previous week, youth who reported riding in a car in the previous week with someone who was smoking were more likely to report that smoking should not be per-

FIGURE 2

Changes in the prevalence of youth in grades 6 to 9 reporting that they were exposed to smoking while riding in a car in the previous 7 days, by region of Canada, 2004, 2006, 2008



Source: 2004, 2006, 2008 Canadian Youth Smoking Surveys.[11,12,13]

[a] New Brunswick, Prince Edward Island, Nova Scotia, Newfoundland and Labrador.

[b] Alberta, Saskatchewan, Manitoba.

mitted around children in cars (OR = 2.73; 95% CI: 2.42–3.07).

Discussion

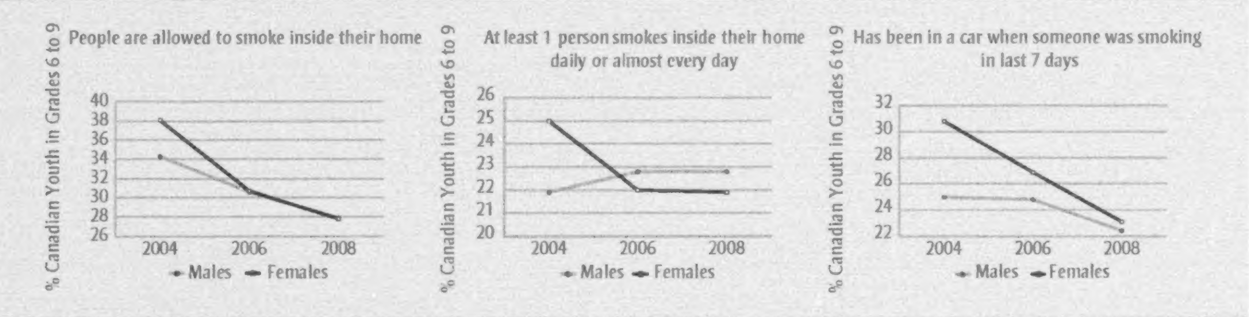
Our study identified that, although the prevalence of youth exposed to SHS in the home and in cars decreased between 2004 and 2008, a substantial number of youth continue to be regularly exposed to SHS. The majority of youth also continue to report that smoking should not be permitted around children in these environments, with youth who are exposed to SHS in the home or in cars more likely to report that smoking should not be permitted around children in these contexts.

It appears that youth may not be able to prevent or limit their SHS exposure in certain contexts, suggesting that, despite the many programs aimed at protecting children from the harm associated with SHS exposure in the home and in cars, stronger and more effective programs or policies are required. For instance, in 2008 the Canadian Lung Association launched the *Stop Smoking in Cars! Our Kids Deserve it!* campaign, a mass media campaign designed to raise awareness and provide parents with information as well as to encourage Canadians to lobby their provincial governments to enact legislation prohibiting smoking in cars when children are present.[15] New initiatives have also been designed to decrease SHS exposure in multi-unit dwellings (e.g. apartments, condos, housing coops, townhouses, etc.). A national website maintained by Smoke-Free Housing Canada provides information and advocates for increased voluntary smoke-free housing options across the country.[16] As yet, no provinces have enacted legislation prohibiting smoking in multi-unit dwellings; however, landlords are legally permitted to voluntarily enact policies making their multi-unit dwellings smoke-free. Although the number of available smoke-free units is limited, anecdotal evidence suggests that demand for smoke-free units is increasing. For instance, the largest landlord in Manitoba, Globe General Agencies, implemented a smoke-free policy in 2006 for all their 60 apartment buildings, which applies to all suites, patios and balconies.[17] The impact of such policies on youth SHS exposure has yet to be evaluated.

Based on our results, which indicate that youth may not be able to prevent or limit their SHS exposure in certain contexts, and there being no safe level of SHS exposure,[2] evaluation of the effectiveness of programs and policies aimed at limiting youth exposure to SHS is needed. In pre-

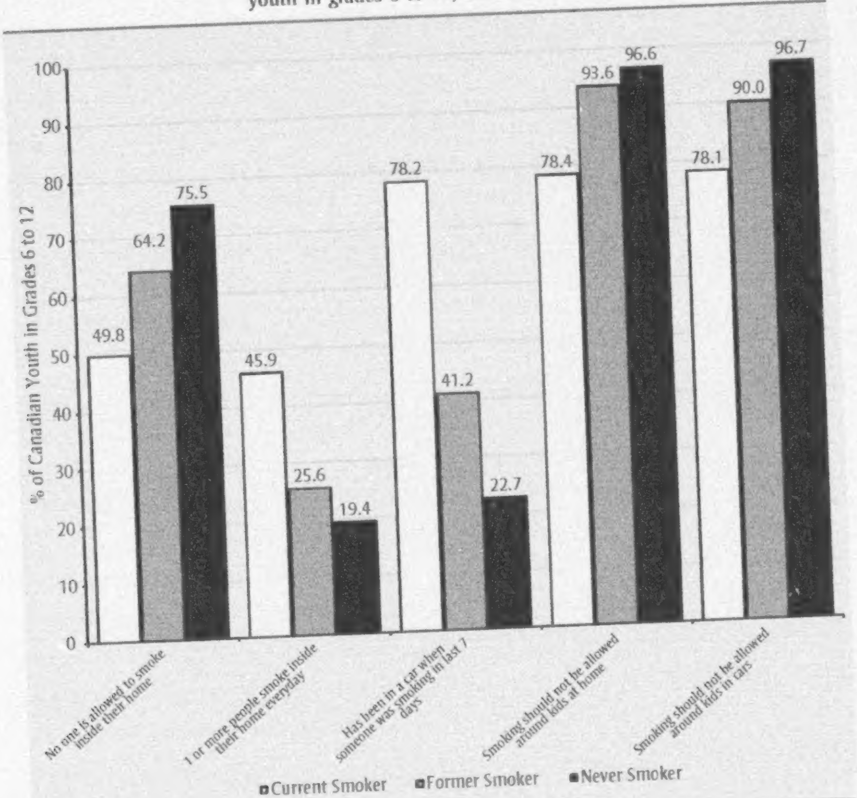
FIGURE 3

Changes in the prevalence of exposure to smoking in homes and in cars among youth in grades 6 to 9 by sex, Canada, 2004, 2006, 2008



Source: 2004, 2006, 2008 Canadian Youth Smoking Surveys.[11,12,13]

FIGURE 4
Prevalence of exposure to smoking and beliefs about smoking in the home and in cars among youth in grades 6 to 12, Canada, 2008



Source: 2008 Canadian Youth Smoking Survey.[11]

and post-campaign surveys designed to examine the effectiveness of the 2006–2007 *Second Hand Smoke in the Home and Car Campaign*, it was found that of those respondents who could recall at least one of the advertisements, 46% reported taking or planning to take action (either by not allowing smoking in their homes or cars, convincing others not to smoke or themselves quitting smoking) as a result of the advertisements.[18] The surveys also found that fewer respondents had misconceptions about the ways in which to reduce SHS exposure in the home. For example, the proportion of respondents who viewed opening a window or using a fan as an effective strategy to reduce SHS exposure decreased by 17% and 10%, respectively.[18] However, although the results of this survey provide promising findings, more systematic research is needed to elucidate the impact of such smoke-free home policies designed to reduce SHS exposure among youth populations.

Additional research is also needed to examine the effectiveness of policies aimed at reducing SHS exposure among youth in cars. For instance, although all Canadian provinces, with the exception of Quebec, have enacted legislation prohibiting smoking in cars when children are present,[19] we could identify only one Canadian study that actually examined the potential impact of these policies. Nguyen[20] compared pre- and post-legislation SHS exposure using data from the Canadian Tobacco Use Monitoring Survey (CTUMS) and the YSS and found, respectively, a 10% and 26% reduction in children's exposure to SHS while riding in cars. Although the results of this study are encouraging, the evidence presented is based on cross-sectional designs so it does not really provide us with robust evidence of the effectiveness of these policies. It would be beneficial to both the research and practice community if appropriate longitudinal research designs, using natural experiments to generate real-world practice-based evidence, were used to evaluate the impact that such emerging policies have when implemented into practice.[21]

The Nguyen[20] study mentioned above did not find evidence of compensatory smoking behaviour in the home as a result of smoke-free car legislation; however, previous research found evidence of increased smoking in the home after bans on smoking in public places had come into effect.[22] Taking into consideration that the home is one of the few places where smoking is still permitted, there is a need to robustly evaluate the impact of recently enacted smoke-free car legislation on compensatory SHS exposure among children. Such evaluations will have important public health impacts with regard to policies and programs aimed at decreasing SHS exposure among youth populations, and may also affect future policies and initiatives aimed at reducing SHS exposure in the home.

Our study also identified that, although the overall prevalence of youth exposed to SHS in the home and in cars has decreased over time, decreases in exposure were more prevalent among female youth than among male youth (Figure 3). In fact, male youths' exposure to SHS in the home every day or almost every day actually increased between 2004 and 2008. The reasons for this apparent sex difference are unknown; however, taking into consideration that rates of smoking are higher among male youth, parents may be more likely to expose their children to SHS if the children are themselves smokers. Or perhaps non-smokers (who are more likely to be female) are more insistent on living in a smoke-free home. The observed differences are worrisome and suggest that additional research is needed to better understand the mechanisms underlying this sex difference. Such research would provide valuable insight for developing targeted programs and policies aimed at protecting male youth.

In conclusion, this study identified that, despite that the majority of youth reported that smoking should not be permitted around children in the home or in cars, a

TABLE 3
Logistic regression analyses examining factors associated with beliefs about smoking in the home and in cars among Canadian youth in grades 6 to 12, 2008, Canada

Parameters	Adjusted odds ratio[a] (95% CI)	
	Model 1 Smoking should not be allowed around kids in the home	Model 2 Smoking should not be allowed around kids in cars
Sex		
Female	1.00	1.00
Male	2.43 (2.20–2.69)**	2.58 (2.33–2.85)**
Youth smoking status		
Current smoker	1.00	1.00
Never smoker	4.26 (3.78–4.79)**	4.14 (3.68–4.65)**
Former smoker	1.82 (1.23–2.71)*	2.02 (1.39–2.94)**
Parental smoking		
No parent(s) smoke	1.00	1.00
At least 1 parent smokes	1.29 (1.14–1.46)**	1.37 (1.21–1.55)**
Rules about smoking in the home		
No one is allowed to smoke in the home	1.00	1.00
Smoking is allowed inside	1.71 (1.50–1.96)**	1.59 (1.39–1.82)**
Number of people who smoke inside the home every day or almost every day		
0	1.00	1.00
≥ 1	1.40 (1.21–1.62)**	1.29 (1.11–1.49)**
Number of days riding in a car with someone who was smoking cigarettes in the past 7 days		
0	1.00	1.00
1–7	2.04 (1.81–2.29)**	2.73 (2.42–3.07)**

Abbreviation: CI, confidence interval.

Notes: Model 1: 1 = No (n = 41 317), 0 = Yes or I don't know (n = 2043).

Model 2: 1 = No (n = 41 435), 0 = Yes or I don't know (n = 2111).

[a] Odds ratios are adjusted for all other variables in the table and for region and grade.

* $p < .01$.

** $p < .001$.

substantial number of youth continue to be regularly exposed to SHS. These findings suggest that youth may not be able to prevent or limit their own exposure, highlighting the need for research examining effective programs and policies intended to reduce exposure in youth populations.

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Are experimental smokers different from their never-smoking classmates? A multilevel analysis of Canadian youth in grades 9 to 12

S. C. Kaai, PhD (1); S. R. Manske, EdD (1, 2); S. T. Leatherdale, PhD (1); K. S. Brown, PhD (1, 2, 3); D. Murnaghan, PhD (4)

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Abstract

Introduction: Understanding the characteristics of experimental smoking among youth is critical for designing prevention programs. This study examined which student- and school-level factors differentiated experimental smokers from never smokers in a nationally representative sample of Canadian students in grades 9 to 12.

Methods: School-level data from the 2006 Canadian Census and one built environment characteristic (tobacco retailer density) were linked with data from secondary school students from the 2008–2009 Canadian Youth Smoking Survey and examined using multilevel logistic regression analyses.

Results: Experimental smoking rates varied across schools ($p < .001$). The location (adjusted odds ratio [AOR] = 0.66, 95% CI: 0.49–0.89) of the school (urban vs. rural) was associated with the odds of a student being an experimental smoker versus a never smoker when adjusting for student characteristics. Students were more likely to be experimental smokers if they were in a lower grade, reported low school connectedness, used alcohol or marijuana, believed that smoking can help people relax, received pocket money each week and had a family member or close friend who smoked cigarettes.

Conclusion: School-based tobacco prevention programs need to be grade-sensitive and comprehensive in scope; include strategies that can increase students' attachment to their school; and address multi-substance use, tobacco-related beliefs and the use of pocket money. These programs should also reach out to students who have smoking friends and family members. Schools located in rural settings may require additional resources.

Keywords: tobacco smoking, youth, prevention, multilevel analysis, Canada

Introduction

Despite the proven harmful outcomes of smoking, youth smoking rates remain high in North America.[1-4] More than 16% and 20% of all annual deaths in Canada and the United States, respectively, result from tobacco-related diseases.[2,5,6] Lifetime smoking often commences as naive experimentation during adolescence and develops into a habit that is difficult to break.[7] Most adult smokers initiated smoking during their teenage years.[3] Evidence also suggests that adolescent smoking behaviour consists of distinct smoking trajectories or stages: susceptible never smokers, experimenters and established (or current) smokers.[8-10] Differentiating between these smoking stages is important to public health practitioners and educators who need to design prevention and intervention programs to match the risk and protective factors in these different stages.

A majority of studies examine established smoking stages.[10-17] Considering that approximately three-quarters of students will experiment with smoking at least once before completing high school[18,19] and that about one-third will become established smokers,[20] understanding the factors that differentiate experimental smokers from never smokers is critical to informing the development of the tobacco control programs designed to discourage students from experimenting with cigarettes.

Many researchers have used the Theory of Triadic Influence (TTI)[21] to understand the complex factors associated with adolescent smoking behaviour. TTI postulates that youth smoking behaviour is influenced by a combination of and interaction between intrapersonal, social context and broader societal influences. Intrapersonal risk factors associated with experimental smoking include age,[22] male sex,[23] use of alcohol or illicit drugs,[22] access to pocket money,[24] low school connectedness,[25] positive attitudes towards smoking[26] and perceiving clear school rules about smoking.[27] Existing social context influences include smoking family members[22,23] or friends.[22,27] The broader societal (or school-level) factors associated with experimental smoking include attending a school with a relatively high smoking rate in senior grades,[27] high

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Author references:

1. School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, Canada
2. Propel Centre for Population Health Impact, University of Waterloo, Waterloo, Ontario, Canada
3. Department of Statistics and Actuarial Science, University of Waterloo, Waterloo, Ontario, Canada
4. School of Nursing, University of Prince Edward Island, Charlottetown, Prince Edward Island, Canada

Correspondence: Susan C. Kaai, School of Public Health and Health Systems, University of Waterloo, 200 University Avenue West, Waterloo, ON N2L 3G1; Tel.: 519-888-4567 ext. 31748; Fax: 519-746-8631; Email: skaai@uwaterloo.ca

density of tobacco retailers around the school[28] and living in a home that does not have a total ban on smoking.[29] Chan and Leatherdale[30] explored the relationship between tobacco retailers and smoking *susceptibility*, *occasional* smoking and *established* smoking. They reported that the number of tobacco retailers located around a school was associated only with smoking susceptibility.[30] Other societal factors associated with *established* (not experimental) smoking include school location[31-33] and neighbourhood socioeconomic status (SES).[31,32,34,35]

Nevertheless, there is a dearth of literature on the influence of school location (urban vs. rural), tobacco retailer density and the SES of the community around a school on students' experimental smoking when adjusting for other student-level factors. Because these school-level factors have previously been found to be associated with established smoking,[31-38] we were interested in finding out whether these factors were also associated with experimental smoking among adolescents. As such, the purpose of this study was to examine which school neighbourhood and student-level characteristics differentiate experimental smokers from never smokers. Understanding these factors will provide new insight for public health practitioners and educators who develop smoking prevention strategies that effectively target youth in different stages of smoking. The authors have also written on the factors associated with current (or established) smoking.[39]

Methods

Design

The 2008-2009 Canadian Youth Smoking Survey (2008 YSS) is a nationally representative cross-sectional, school-based survey that is used to measure the determinants of youth smoking behaviour. It is a valid and reliable machine-readable, pencil and paper study.[40] (See Elton-Marshall et al.[41] and www.yss.uwaterloo.ca for detailed information on the survey development, design, survey weights and data collection protocol.) In brief, the target population consisted of all young Canadian residents in the appropriate grades attending public or private schools in all 10 provinces in Canada. The sample design was based on a stratified multistage design. The survey took about 20 to 30 minutes, and to ensure confidentiality, students placed completed questionnaires in an envelope that was sealed and placed in a larger classroom envelope. The University of Waterloo Office of Research and Ethics approved the survey methods.

Participants

The sample for this study was from the secondary school portion of 2008 YSS. This portion was administered to all sampled grade 9 to 12 students (n = 29 296) attending 133 schools from all 10 Canadian provinces. The student response rate was 73.2%.[41] Our study used only the subset of 18 072 students who were experimental or never smokers.

Data sources and measures

Outcome variables

Based on other research,[13,28,42,43] we defined "experimental smokers" as those who had smoked in the last 30 days before the survey but had not smoked 100 cigarettes in their lifetime. This group was compared with "never smokers," defined as those who reported never having smoked even a puff of a cigarette.[40]

Student (intrapersonal and social context) and school-level (broader societal) correlates

Selection of all variables was guided by TTI[21] and our literature review. We coded the intrapersonal factors (sex, grade, alcohol or marijuana use, pocket money, school connectedness, knowledge and attitude towards tobacco, and perception of school smoking rules) and social context measures (parents', siblings' and friends' smoking status) as listed in Table 1. Two school-level neighbourhood characteristics from the 2006 Canadian Census (i.e., location [urban vs. rural] and median household income, which is a proxy measure for school neighbourhood SES) were linked with the 2008 YSS dataset, as has been done by other researchers.[44,45] Both school location and median household income data were derived from school postal codes using the Postal Code Conversion File that links between the postal code and Statistics Canada's standard 2006 Census geographical areas[46] (see Table 1). The 2008/09 Enhanced Points of Interest (EPOI) data file from Desktop Mapping Technologies Inc.[47] provided numerical data on the number of tobacco retailers located within a 1-kilometre radius of each school (Table 1).

Statistical data analyses

We used multilevel logistic regression to analyze the two-level nested data because it accounts for the clustering (interdependence) of students within schools by allowing the model intercept to vary across schools.[48] This produces accurate standard errors and reduces the likelihood of type 1 error.[49] Like other researchers,[27] we used a four-step modelling procedure. Model 1 is a null model computed to assess whether there was significant within-cluster interdependence to warrant the use of a multilevel approach. The main purpose for Model 2 was to determine the school-level variables that would directly affect the likelihood of a student being an experimental smoker rather than a never smoker. Model 3 used a random coefficient regression model to assess the strength of the direct effects of both the school- and student-level correlates.

Model 4 was developed to assess the contextual interactions between the school-level and student-level predictor variables. The SAS PROC GLIMMIX[50] procedure provided the initial estimates that were used in the PROC NLMIXED analysis for each model. Predictor variables that were not significant at $p < .05$ were removed until the final model only contained predictor variables that were significant at that p value. The intraclass correlation (ICC) measures the proportion of the total variance that occurs between schools. The σ^2_μ denotes the school-level variance, whereas the logistic distribution for the individual residual implies a

TABLE 1
List of variables included in the analysis

TTI domain	Specific question asked or how variable was derived	Coding for analysis
Student-level intrapersonal		
Grade	What grade are you in?	9, 10, 11, 12
Sex	Are you female or male?	0 = female 1 = male
Pocket money	About how much money do you usually get each week to spend on yourself or save?	0 = $0 1 = $1–20 2 = $21–100 3 = $101 +
Alcohol use	In the last 12 months, how often did you have a drink of alcohol that was more than just a sip? 1 = I have never drank alcohol; 2 = I did not drink alcohol in the last 12 months; 3 = I have only had a sip of alcohol; 4 = Every day; 5 = 4 to 6 times a week; 6 = 2 or 3 times a week; 7 = Once a week; 8 = 2 or 3 times a month; 9 = Once a month; 10 = Less than once a month. 11 = "I do not know" was not a valid response	0 = I have never drank alcohol 1 = Any use (options 2 to 10)
Marijuana use	In the last 12 months, how often did you use marijuana or cannabis? (a joint, pot, weed, hash...). 1 = I have never used marijuana; 2 = I have used marijuana but not in the last 12 months; 3 = Every day; 4 = 4 to 6 times a week; 5 = 2 or 3 times a week; 6 = Once a week; 7 = 2 or 3 times a month; 8 = Once a month; 9 = Less than once a month. 10 = "I do not know" was not a valid response	0 = I have never used marijuana 1 = Any use (options 2 to 9)
School connectedness	Students were asked whether they 1) felt close to people at school; 2) felt part of their school; 3) were happy at school; 4) felt that the teachers at school treated them fairly; and 5) felt safe at school. The responses were given on a 4-point Likert Scale. The five items of the school connectedness score were summed to give a final score from 0 to 5. Higher scores represented greater perception of school connectedness. This summation was consistent with previous literature, and the internal consistency of this scale was adequate (α = 0.86).[16]	0 = strongly disagree/disagree 1 = strongly agree/agree
Knowledge	Do people have to smoke for many years before it will hurt their health?	0 = no or I do not know 1 = yes
	Is there any danger to your health from an occasional cigarette?	0 = no or I do not know 1 = yes
Beliefs	Does smoking help people relax?	0 = no or I do not know 1 = yes
School rules	This school has a clear set of rules about smoking for students to follow. The responses were given on a 4-point Likert Scale, i.e. true, usually true, usually false, false and recoded as shown in right-hand column.	0 = usually false/false/I do not know 1 = true/usually true
Student-level social context		
Parent(s) smoke(s)	Do any of your parents, step-parents, or guardians smoke cigarettes?	0 = no or I do not know 1 = yes
Sibling(s) smoke(s)	Do any of your brothers or sisters smoke cigarettes?	0 = no or I do not know or I have no brothers or sisters 1 = yes
Friend(s) smoke(s)	How many of your closest friends smoke cigarettes?	0 = 0, 1 = 1, 2 = 2, 3 = 3, 4 = 4, 5 = 5 or more

Continued on the following page

variance of $\pi^2/3 = 3.29$. This formula considers that the observed binary response actually represents a threshold continuous variable where 0 is observed below the threshold and 1 above.[48]

All analyses used SAS version 9.2 (SAS Institute Inc., Cary, NC, US).[50]

Results

Student- and school-level characteristics

Of the sample of grade 9 to 12 students, 16 044 (54.8%) were classified as never smokers and 2028 (6.9%) were classified as experimental smokers. The remainder were not included in our study. Boys made up 51% of the sample. The prevalence of experimental smoking did not differ by sex ($\chi^2 = 0.02$; $p = 0.89$; $df = 1$). With that exception, all other student characteristics tested were significant ($p < .001$).

TABLE 1 (continued)
List of variables included in the analysis

TTI domain	Specific question asked or how variable was derived	Coding for analysis
School-level broader societal		
Location	School location was derived from the school postal codes using the Postal Code Conversion File that provided a link between the postal code and Statistics Canada's standard Census geographical areas.[46] For the analysis, areas were classified as rural (Census population < 50 000) or urban (Census population ≥ 50 000).	0 = rural 1 = urban
SES	2006 Census median household income data were used as a proxy measure for school-level SES, as has been done in previous studies.[44] This variable is continuous and the unit change was in intervals of $10 000 for ease of interpretation.	Numeric data by units of $10 000
Tobacco retailer density	2008/09 DMTI and EPOI data provided numeric data about the number of tobacco retailers within a 1 km radius of each sampled secondary school. The EPOI data file consists of a national database of more than 1.6 million Canadian business and recreational points of interest (http://www.dmtispatial.com). DMTI-EPOI data were obtained through geocoding the address for each participating school using Arcview 3.3 software.[47] A 1 km radius was selected as representative of the distance most high school students would walk to and from their school.[44]	Numeric (each 1 unit change)

Abbreviations: DMTI, Desktop Mapping Technologies Inc.; EPOI, Enhanced Points of Interest; SES, socio-economic status; TTI, Theory of Triadic Influence; YSS, Youth Smoking Survey.

The proportion of experimental smokers increased from grade 9 to 12; as the number of friends who smoke increased from 1 to 5; and as the amount of weekly pocket money increased (Table 2). The percentage of experimental smokers who used marijuana (36.8%) or alcohol (14.2%) was strikingly higher than the percentage of experimental smokers who did not use marijuana (2.4%) or alcohol (1%).

Of the total sample of 133 secondary schools, 69 were located in urban areas. The average experimental smoking rate among students in grades 9 to 12 in the 133 secondary schools was 6.2% (range, 0%–17.4%), and this was lower in urban schools (5.7%) than in rural schools (6.6%). The percentage of experimental smokers (11.1%; 1325/11 977) in urban schools did not significantly differ from that in rural schools (11.5%; 703/6095). The mean number of tobacco retailers within a 1-kilometre radius of the schools was 5.8 (standard deviation [SD] 10; range, 0–49 km). The mean household income within the postal code around each school was $56 424 (SD $14 574; range, $30 784–$97 706).

Multilevel analysis of experimental smoking

Table 3 shows results of the multilevel logistic regression analyses. The results from the null model (Model 1) showed a significant between-school random variation (Estimate [Standard Error (SE)] = 0.23 [0.05]; $p < .001$) in the likelihood of experimental smoking among grade 9 to 12 students. The estimates suggest that the school a student attends accounts for 6.5% of the variability in their likelihood of being an experimental smoker versus a never smoker. Model 2 results show that only school location was important, as students in urban schools were less likely to be experimental smokers than never smokers (adjusted odds ratio [AOR] = 0.74, 95% CI: 0.60–0.91) compared to students in rural schools. This neighbourhood characteristic explained 11.9% of the between-school variability in the likelihood of a student being an experimental smoker. The number of tobacco retailers within a 1-kilometre radius around a school was not associated (AOR = 0.99, 95% CI: 0.97–1.01) with experimental smoking. Additionally, the median household income that was used as a proxy measure for school neighbourhood SES was not associated (AOR = 0.93, 95% CI: 0.86–1.01) with the likelihood of a student being an experimental smoker versus a never smoker.

Model 3 identified the school-level characteristics that were significantly associated with the odds of a student being an experimental smoker when adjusting for student-level characteristics. When we first examined each of the three school-level variables separately (adjusting for the student-level variables), the location (AOR = 0.62, 95% CI: 0.46–0.82; urban vs. rural; data not shown) and the neighbourhood SES (AOR = 0.88, 95% CI: 0.79–0.98; data not shown) where schools were located were significantly associated with the odds of a student being an experimental smoker. However, when we put all the school-level (location, SES and number of tobacco retailers) and student-level variables in one final model, only school location (urban vs. rural) remained significant (AOR = 0.66, 95% CI: 0.49–0.89; see Table 3). None of the contextual interactions in Model 4 (results not shown) were associated with the outcome variable.

In summary, the final model suggests that there were no sex differences (AOR = 1.00, 95% CI: 0.86–1.16) in the likelihood of a student being an experimental smoker versus a never smoker. The odds of a student being an experimental smoker decreased when they attended an urban school (AOR = 0.66, 95% CI: 0.49–0.89) compared with a rural school. In terms of student-level findings, students who were in grade 10 and 11 were less likely to be experimental smokers than never smokers compared with those who were in grade 9 (grade 10 vs. grade 9: AOR = 0.75, 95% CI: 0.61–0.93; Grade 11 vs. grade 9: AOR = 0.71, 95% CI: 0.57–0.89). On the other hand, the odds of a student being an experimental smoker versus a never smoker increased with the amount of weekly pocket money they had to spend ($1–$20 vs. no pocket money: AOR = 1.59, 95% CI: 1.20–2.11; > $100 vs. no pocket money: AOR = 2.23, 95% CI: 1.66–2.99); a student's belief that smoking can help people relax (AOR = 3.37, 95% CI: 2.85–3.97); a student's perception that there are clear school rules on smoking (AOR = 1.56, 95% CI: 1.27–1.92); low school connectedness (AOR = 0.87, 95% CI: 0.83–0.92); and alcohol use (AOR = 3.51, 95% CI: 2.41–5.12). Marijuana use appeared to be very important as the odds of a student being an experimental smoker was more than 15 times higher (AOR = 15.4, 95% CI: 12.96–18.26) if the student reported using marijuana.

In terms of social context correlates, a student who reported that at least one parent (AOR = 1.29, 95% CI: 1.11–1.50) or sibling (AOR = 1.45, 95% CI: 1.22–1.73) smoked cigarettes was at an increased risk of being an experimental smoker versus a never smoker. In addition, the odds of a student being an experimental smoker increased significantly as the number of closest friends who smoke cigarettes increased, that is, AOR ranged from 3.69 (95% CI: 2.96–4.59) for one close friend versus no friends who smoke) to AOR of 10.52 (95% CI: 7.10–15.60) for four close friends versus no friends who smoke. Between schools variation was not accounted for by these student-level factors. School-to-school variation remained significant even after adjusting for student-level factors.

TABLE 2

Descriptive statistics (weighted) for secondary students by smoking category, Canadian Youth Smoking Survey, 2008 (n = 18 072)

Characteristics	Experimental smokers (n = 2028)	Never smokers (n = 16 044)
Sex, %		
Male	11.2	88.8
Female	11.3	88.8
Grade, %		
9	8.4	91.6*
10	9.7	90.3
11	12.5	87.5
12	15.7	84.3
Weekly pocket money in $, %		
0	4.8	95.2*
1–20	8.8	91.2
21–100	14.6	85.4
> 100	17.4	82.6
Alcohol use, %		
No	1.0	99.0*
Yes	14.2	85.8
Marijuana use, %		
No	2.4	97.6*
Yes	36.8	63.2
Do people have to smoke for many years before it will hurt their health?, %		
No	15.9	84.1*
Yes	9.9	90.1
Is there any danger to your health from an occasional cigarette?, %		
No	15.6	84.4*
Yes	9.7	90.3
Does smoking help people relax?, %		
No	4.4	95.6*
Yes	18.4	81.6
Mean school connectedness score (SD)	3.75 (1.47)	4.20 (1.27)*
Perception of clear smoking rules, %		
No	7.9	92.1*
Yes	12.1	87.9
At least one parent smokes, %		
No	8.4	91.7*
Yes	16.6	83.4
At least one sibling smokes, %		
No	9.3	90.7*
Yes	22.8	77.2
Number of friends who smoke, %		
0	2.4	97.6*
1	16.6	83.4
2	25.5	74.5
3	36.2	63.8
4	32.4	67.6
5	41.6	58.4

Abbreviation: SD, standard deviation.

Note: Weighted Chi-square tests used for categorical variables and independent t-tests used for continuous variable i.e. mean school connectedness score.

* $p < .001$.

TABLE 3

Multilevel logistic regression analysis of the student- and school-level variables that were related to the odds of being an experimental smoker versus a never smoker, Canadian Youth Smoking Survey, 2008 (n = 18 072)

Characteristics	Model 1[a]	Model 2[b]	Model 3[c]
	Model estimates (SE)	AOR (95% CI)	AOR (95% CI)
Student-level intrapersonal factors			
Sex			
Girl (Ref)	—	—	1.0
Boy	—	—	1.00 (0.86–1.16)
Grade			
9 (Ref)	—	—	1.0
10	—	—	0.75 (0.61–0.93)*
11	—	—	0.71 (0.57–0.89)*
12	—	—	0.82 (0.64–1.05)
Weekly pocket money, $			
0 (Ref)	—	—	1.0
1–20	—	—	1.59 (1.20–2.11)*
21–100	—	—	2.03 (1.54–2.68)**
> 100	—	—	2.23 (1.66–2.99)**
Does smoking help people relax?			
No (Ref)	—	—	1.0
Yes	—	—	3.37 (2.85–3.97)**
Do people have to smoke for many years before it will hurt their health?			
No (Ref)	—	—	1.0
Yes	—	—	0.66 (0.55–0.79)**
Is there any danger to your health from an occasional cigarette?			
No (Ref)	—	—	1.0
Yes	—	—	0.62 (0.52–0.73)**
There are clear school rules on smoking			
No (Ref)	—	—	1.0
Yes	—	—	1.56 (1.27–1.92)**
Alcohol use			
No (Ref)	—	—	1.0
Yes	—	—	3.51 (2.41–5.12)**
Marijuana use			
No (Ref)	—	—	1.0
Yes	—	—	15.4 (12.96–18.26)**
Mean connectedness score	—	—	0.87 (0.83–0.92)**
Student-level social context factors			
At least one parent smokes			
No (Ref)	—	—	1.0
Yes	—	—	1.29 (1.11–1.50)*
At least one sibling smokes			
No (Ref)	—	—	1.0
Yes	—	—	1.45 (1.22–1.73)**

Continued on the following page

Discussion

Since some youth experience nicotine dependence within as little as a day after first inhaling cigarette smoke,[22] dissuading them from experimenting with cigarettes is an important way of preventing smoking. Our study identified four notable findings valuable to future tobacco control prevention programming. First, the likelihood of a student being an experimental smoker varied significantly across schools, a finding consistent with other research on youth smoking behaviour.[27,51] This suggests that the characteristics of a student's school are associated with the likelihood that they will be an experimental smoker above and beyond the individual student's characteristics. Although school accounted for a modest 6.5% of the variability, when distributed across the broader secondary school population in Canada, it represents a notable amount of variation that cannot be ignored.

Second, our results supported TTI and also expanded on existing literature[31-35] by showing that variables related to school location (i.e. rural vs. urban setting and the school neighbourhood SES [when analyzed alone]) were associated with experimental smoking after controlling for student-level characteristics. However, stronger and more in-depth studies would be necessary to help public health practitioners identify the specific characteristics in rural schools or schools located in low SES neighbourhoods that predispose students to experimental smoking.[31-35] Moreover, school location (urban vs. rural), neighbourhood SES and tobacco retailer density only explained part of the between-school variability; more surveillance activities are required to evaluate other types of school-level data such as linkages with the community and media and the role of school-based tobacco control programs and policies.[42,52,53]

In contrast to other researchers' findings on experimental smoking,[28] we found that the number of tobacco retailers located around secondary schools was not associated with the outcome variable. This suggests that the number of tobacco retailers around a school is more important for those students who are susceptible

TABLE 3 (continued)
Multilevel logistic regression analysis of the student- and school-level variables that were related to the odds of being an experimental smoker versus a never smoker, Canadian Youth Smoking Survey, 2008 (n = 18 072)

Characteristics	Model 1[a]	Model 2[b]	Model 3[c]
	Model estimates (SE)	AOR (95% CI)	AOR (95% CI)
Number of friends who smoke			
0 (Ref)	—	—	1.0
1	—	—	3.69 (2.96–4.59)***
2	—	—	5.87 (4.69–7.35)***
3	—	—	8.56 (6.59–11.12)***
4	—	—	10.52 (7.10–15.60)***
5	—	—	9.51 (7.59–11.91)***
Societal (school-level) factors			
Tobacco retailer density (each 1 unit change)	—	0.99 (0.97–1.01)	0.99 (0.97–1.02)
Location			
Rural (Ref)	—	1.0	1.0
Urban	—	0.74 (0.60–0.91)*	0.66 (0.49–0.89)*
Median household income (each $10 000 unit change)	—	0.93 (0.86–1.01)	0.92 (0.82–1.03)
Random variance (estimate [SE])	0.23 (0.05)***	0.20 (0.04)	0.28 (0.07)
Intraclass Correlation[d] $\sigma^2_\mu/(\sigma^2_\mu + \pi^2/3)$	0.065	0.056	0.079

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval; Ref, reference category; SE, standard error.

Note: Dependent variable: Experimental smoker=1 and Never smoker=0.

[a] Random intercept only (null model computed to assess whether there was significant within-cluster interdependence to warrant the use of a multilevel approach).

[b] School-level variables only that would directly affect the likelihood of a student being an experimental smoker compared to a never smoker.

[c] School- and student-level variables.

[d] Measures of the proportion of the total variance that occurs between schools.

* $p < .05$.

*** $p < .001$.

to smoking[30] or established smokers[36-39] than for students who are still experimenting with cigarettes. TTI variables drawn from the individual level may offer an explanation. Previous studies found that regular smokers were more likely to use retail sources, that is, buy cigarettes from tobacco retailers while experimenters used social sources such as "borrowing" cigarettes from friends or family, which made the location of retailers less important in our study.[54]

Third, the intrapersonal findings (i.e. grade, attitudes, pocket money, perception of anti-smoking rules, alcohol and marijuana use, school connectedness) from our study were consistent with existing literature.[21,26] For example, students who reported pro-smoking attitudes, such as believing that smoking can help people relax, were more likely to be experimental smokers. This is not surprising; the TTI posits that adolescents' perceptions and beliefs represent the most proximal level of influence because they reflect the adolescents' ability to resist pressures to initiate and progress into advanced smoking behaviour.[21] The amount of pocket money students had available was also associated with experimental smoking, a finding consistent with that of Mohan et al.[24] Parents and guardians who give their adolescent children pocket money need to understand how this money is spent.

Our finding about students' perceptions of anti-smoking school rules is consistent with that of other researchers who indicated that tobacco control school policies or rules are not effective on their own but that suitable enforcement is necessary.[14,16] Our study did not assess enforcement; however, plausible explanations include that existing smokers tend to notice anti-smoking policies relevant to them or that schools develop and implement policies in response to higher rates of tobacco use.[55] Perhaps the experimental smokers in our study reflect individual differences in oppositional defiant tendencies or sensation-seeking behaviour (we did not measure these characteristics), as reported in other studies.[56,57]

Our finding that alcohol use predicted experimental smoking is consistent with that of other studies.[22] Most striking was the finding that if a student reported using marijuana the odds of them being an experimental smoker (vs. a never smoker) were more than 15 times higher (AOR 15.4, 95% CI 12.96–18.26) than for those students who did not report usage. Although it is not possible to determine whether marijuana use precedes tobacco use or vice versa using our cross-sectional data, this finding highlights adolescent multi-substance or multi-risk behaviour and the importance of schools prioritizing the prevention of substance use (whether tobacco, marijuana, alcohol or combinations of substances) by optimizing limited resources through the use of multipronged strategies that target multiple substance use.[58-63] This approach improves students' educational outcomes and also encourages healthy social behaviours that help students resist substance abuse and feel more connected to their school.[63-65] Consistent with other research,[25,66] our results show that students who feel more connected to their school are less likely to initiate risky behaviour such as tobacco use. It is also consistent with current efforts in Canada (e.g. Pan-Canadian Joint Consortium for School Health[64] and New Brunswick Wellness Strategy[65]) to address "upstream" issues in school settings to create healthy environments and provide skills to enable youth to resist any form of substance use.

Fourth, the results about friends and family who smoke are consistent with existing evidence[22,23,27] and support the TTI,[21] which posits that this group forms the immediate social environment that contributes to the social pressure (e.g. by reinforcing the behaviour through offering cigarettes or modelling smoking) on adolescents to experiment with tobacco. The implication for this finding is that school-based tobacco control programs should equip students with the necessary information and skills to deal with any form of pressure that may predispose them to experimental smoking.[8]

That students in grades 10 and 11 were less likely to be experimental smokers (vs. never smokers) than those who in grade 9 was consistent with results of studies that examined established smoking.[20] Students in higher grades may have moved on from experimental smoking to regular or established smoking. This suggests that school-based prevention strategies should be implemented early, in elementary school, and sustained into high school and post-secondary years (subject to availability of resources). Unlike one Chinese study,[23] we did not find sex to be associated with the outcome variable. However, although boys did not differ from girls in our analyses, their decisions to experiment with smoking may have different influences,[67] and to the extent that this is true, school-based interventions may still have to consider sex.

Strengths and limitations

The strengths of this study include our use of nationally representative data of Canadian adolescents in different smoking stages. This study is also guided by a comprehensive theory (TTI) that targets broader and multiple influences of health-related behaviours including tobacco use.[21] We used a two-level multilevel logistic regression analysis to account for the clustering of students within the same school to reduce the likelihood of type 1 error.[48]

The study findings do not permit causal inferences due to the temporal sequence of our cross-sectional data. While self-report data are subject to response bias, the survey methodology ensured both student confidentiality and that the data were reliable and valid.[41-43] The exclusive reliance on Census data for school SES (proxy measure) has been criticized; instead the use of multiple neighbourhood measures such as physical and socio-demographic characteristics is encouraged.[44] Future research should explore TTI further by investigating the relationship between experimental smoking and other student- and school-level variables that were not available in our dataset.

Conclusion

Our findings expand on the knowledge about the student- and school-level characteristics that influence experimental smoking among secondary school students. Specifically, the characteristic of the school a student attends (i.e. being located in a rural location) can increase the likelihood of experimental smoking above and beyond individual-level influences. Our study highlights the importance of designing school-based tobacco control prevention policies and programs that are grade-sensitive and comprehensive in scope, including strategies that can increase students' attachment to their school and address multi-substance use, tobacco-related beliefs and the use of pocket money. These programs should also reach out to students who have friends and family members who smoke. Schools in rural areas may require additional resources.

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The views expressed herein do not necessarily represent the views of Health Canada.

Conflict of interest

All authors declare that they have no conflict of interest.

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A comprehensive profile of the sociodemographic, psychosocial and health characteristics of Ontario home care clients with dementia

M. Vu, MSc (1, 2); D. B. Hogan, MD (3, 4); S. B. Patten, MD, PhD (4); N. Jetté, MD, MSc (4, 5); S. E. Bronskill, PhD (6, 7); G. Heckman, MD (2); M. J. Kergoat, MD (8); J. P. Hirdes, PhD (2); X. Chen, MMSc (2); M. M. Zehr, BSc (1); C. J. Maxwell, PhD (1, 2, 4, 6)

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Abstract

Introduction: This study provides a comprehensive summary of the sociodemographic, psychosocial and health characteristics of a large population-based cohort of Ontario home care clients (aged 50 years and over) with dementia and examines the variation in these characteristics in those with co-existing neurological conditions.

Methods: Clients were assessed with the Resident Assessment Instrument-Home Care (RAI-HC) between January 2003 and December 2010. Descriptive analyses examined the distribution of these characteristics among clients with dementia relative to several comparison groups, as well as clients with other recorded neurological conditions.

Results: Approximately 22% of clients (n = 104 802) had a diagnosis of dementia (average age 83 years, 64% female) and about one in four within this group had a co-existing neurological condition (most commonly stroke or Parkinson disease). About 43% of those with dementia did not live with their primary caregiver. Relative to several comparison groups, clients with dementia showed considerably higher levels of cognitive and functional impairment, aggression, anxiety, wandering, hallucinations/delusions, caregiver distress and a greater risk for institutionalization. Conversely, they showed a lower prevalence of several chronic conditions and lower levels of recent health service use. Depressive symptoms were relatively common in the dementia and other neurological groups.

Conclusion: Clients with co-existing neurological conditions exhibited unique clinical profiles illustrating the need for tailored and flexible home care services and enhanced caregiver assistance programs.

Keywords: dementia, Alzheimer disease, neurological disorders, mental health, home care

Introduction

Current global estimates suggest that approximately 35.6 million people have a form of dementia, including Alzheimer disease.[1] Within Canada, approximately half a million people have dementia with prevalence estimates increasing exponentially beyond the age of 65 years.[2] Aside from its personal cost, the ongoing care of those with dementia poses a significant societal and economic burden both in terms of care provided by family as well as formal care services and costs.[3-6] Although relatively few seniors will require costly institutional care as they age,[7] the risk increases significantly for older adults with dementia.[8] The provision of timely, appropriate and co-ordinated home care services to older Canadians with dementia may help mitigate institutional risk and costs while supporting seniors' preferences to remain at home surrounded by familiar settings and social networks for a longer period of time.[9]

Of the estimated 1 million Canadians receiving home care services at any given time,[10] over three-quarters (82%) are 65 years or older,[11] and about 20% have Alzheimer disease or other dementias.[12] Comprehensive understanding of the social, mental and physical health needs of older Canadians with dementia receiving community-based care is required to ensure responsive care planning and the optimal management of this growing and vulnerable population. A thorough examination of client characteristics and care needs may further facilitate the identification of supportive strategies for over-

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Author references:

1. School of Pharmacy, University of Waterloo, Waterloo, Ontario, Canada
2. School of Public Health & Health Systems, University of Waterloo, Waterloo, Ontario, Canada
3. Division of Geriatric Medicine, Department of Medicine, University of Calgary, Calgary, Alberta, Canada
4. Department of Community Health Sciences and Institute for Public Health, University of Calgary, Calgary, Alberta, Canada
5. Department of Clinical Neurosciences and Hotchkiss Brain Institute, University of Calgary, Calgary, Alberta, Canada
6. Institute for Clinical Evaluative Sciences, Toronto, Ontario, Canada
7. Institute of Health Policy, Management & Evaluation, University of Toronto, Toronto, Ontario, Canada
8. Centre de recherche, Institut universitaire de gériatrie de Montréal, Département de médecine, Université de Montréal, Montréal, Quebec, Canada

Correspondence: Colleen J. Maxwell, School of Pharmacy, University of Waterloo, 200 University Avenue West, Waterloo, ON N2L 3G1; Tel.: 519-888-4567 ext. 21396; Fax: 519-883-7580; Email: colleen.maxwell@uwaterloo.ca

whelmed family caregivers.[13] Previous studies have primarily examined the care needs and service use of older adults with dementia living in residential or long-term care facilities in the United States.[14-16] Recent population-based studies of community-dwelling seniors with dementia across Canada are scarce. Earlier work (largely derived from the 1991–2001 Canadian Study of Health and Aging[17,18]) may not reflect changes in the complexity of care or service needs facing people with dementia and their caregivers. There is also a paucity of research characterizing those who have dementia along with a comorbid neurological illness. This is an important sub-population given the probable rise in caregiver stress and health service use due to the increasing severity of symptoms related to co-occurring neurological conditions.[19,20]

To address current knowledge and policy gaps relevant to the quality of life and care of older Canadians with dementia, our objectives were to (1) provide a comprehensive summary of the sociodemographic, psychosocial and health characteristics of a large population-based cohort of home care clients with dementia relative to several comparison groups; and (2) explore the variation in these characteristics in clients with dementia alone compared with those with co-existing neurological conditions (e.g. dementia with stroke or Parkinson disease).

Methods

Design and Sample

This cross-sectional study is part of a larger research program (Innovations in Data, Evidence, and Applications for Persons with Neurological Conditions, or ideas PNC)[21] designed to provide prevalence estimates and clinical profiles of people with one or more of 10 priority neurological conditions receiving continuing care services.

Our sample included all home care clients in Ontario aged 50 years or older assessed with the Resident Assessment Instrument-Home Care (RAI-HC) between January 2003 and December 2010. The RAI-HC provides a standardized comprehensive assessment of a client's sociodemographic characteristics, physical and cognitive status, health conditions and selected diagnoses, behavioural problems, medication use and receipt of specific services. Since 2002, the RAI-HC has been mandated for all long-stay (i.e. expected to receive services for more than 60 days) home care clients with assessment data captured in the Ontario Association of Community Care Access Centres (OACCAC) database.

We first excluded RAI-HC assessments completed in an inpatient acute care setting for the purpose of placement (7.6% of all assessments) and then selected the most recent assessment available for clients (n = 520 479). This sample was reduced to 488 374 following our age restriction (50–115 years). We excluded those assessed prior to 2003 (0.02%) due to concerns about data completeness during this initial implementation phase. The final analytical sample included 488 290 unique clients.

The University of Waterloo houses de-identified copies of OACCAC data as part of a license agreement between interRAI and the Canadian Institute for Health Information.[22] These holdings are governed by regulations to protect personal privacy but do not require individual client consent (beyond that already obtained by contributing organizations during assessment).

Our study received research ethics approval from the University of Waterloo's Office of Research Ethics (project #17045).

Measures

Trained case managers, usually nurses or social workers, perform routine RAI-HC assessments using the best available information (e.g. clinical judgement; case discussions with attending physicians, other formal care providers and family members; health record review). The reliability and validity of the instrument has been established across a range of populations and settings.[23-26]

We examined the following RAI-HC items: clients' sociodemographic status (age, sex, marital status, whether trade-offs in purchasing needed treatment were made due to limited funds); psychosocial characteristics (availability of a caregiver, living arrangements, presence of caregiver distress); health status (cognitive and functional impairment, health instability, depressive and other neuropsychiatric symptoms, behavioural problems, select disease diagnoses); recent hospitalization and emergency department visits; and medication use in the previous week (i.e. 9+ medications, 1+ medications from selected classes [antipsychotic, anxiolytic, antidepressant, hypnotic, cholinesterase inhibitor and/or memantine use]). Details regarding all medications used in the previous week are manually recorded from containers, verified with clients/caregivers and transcribed electronically.

We examined five validated scales derived from RAI-HC items: Cognitive Performance Scale (CPS) (range 0–6);[27] Activities of Daily Living (ADL) Self-Performance Hierarchy Scale (range 0–6);[24,28] Changes in Health, End-stage Disease and Signs and Symptoms (CHESS) Scale (range 0–5);[29,30] Method for Assigning Priority Levels (MAPLe) (range 1–5);[31] and Depression Rating Scale (DRS) (range 0–14).[32,33] We also examined a modified Aggressive Behaviour Scale (ABS)[34] derived from the sum of any occurrence of four behaviours (verbal abuse, physical abuse, socially inappropriate behaviour or resisting care) in the previous three days, and a summary measure of impairment in four instrumental ADLs (some or greater difficulty with meal preparation, managing finances, managing medications and transportation). Higher scores on all these scales indicate more severe impairment.

The CPS reflects level of cognitive impairment and has been validated against the Mini-Mental State Examination.[35] It includes four items (short-term memory, cognitive skills for daily decision making, expressive communication and eating self-performance) and ranges from 0 (intact) to 6 (very severe impairment).[27,35] The CHESS scale ranges from 0 (stable) to 5 (unstable health) and combines symptoms (vomiting, dehydration, decline in food/fluid intake, weight loss, shortness of breath, edema) with items capturing recent decline (in cognition and ADL) and end-stage disease. Higher CHESS scores predict mortality, institutionalization and hospitalization in older adults across care settings.[29,36,37] The MAPLe differentiates clients into five priority levels (low to very high) based on level of cognitive and ADL impairment, behavioural issues, environmental concerns and self-reliance. Higher levels are predictive of institutionalization and caregiver stress.[31]

The RAI-HC contains a diagnostic checklist for commonly occurring conditions in an older population. Conditions were considered present if a doctor diagnosed them, a home care professional was required to treat or monitor them, or the disease was a reason for hospitalization in the previous 90 days. Neurological diagnoses captured on this checklist include dementia (Alzheimer disease and/or other dementias), multiple sclerosis (MS), Parkinson disease/Parkinsonism (PD), traumatic brain injury (TBI, referred to as "head trauma" on the instrument) and stroke. There are open-ended fields for free-text entry of diagnoses not on the checklist. Six neurological conditions were coded as present/absent based on a review of all free-text entries: epilepsy/seizure disorder, Huntington disease (HD), muscular dystrophy (MD), cerebral palsy (CP), spinal cord injury (SCI) and amyotrophic lateral sclerosis (ALS). The free-text terms were defined by consensus of an expert review committee including neurologists, psychiatrists and geriatricians. The conditions listed above (excluding stroke) are the 10 priority neurological diagnoses identified by the Public Health Agency of Canada for the ideas PNC program. We included stroke in our analyses because it is a common and disabling condition in older people.

Data supporting the accuracy of diagnoses recorded on RAI instruments have been published elsewhere.[37-39] Wodchis et al.[38] showed sensitivities of 0.80 or greater for several common conditions in Ontario complex continuing care settings (e.g. stroke, diabetes, cancer, chronic obstructive pulmonary disease [COPD], heart failure). Comparable sensitivity estimates were observed for PD (0.87), Alzheimer disease (0.85, allowing for a check of either "Alzheimer's" and/or "Dementia other than Alzheimer's Disease" on the RAI), CP (0.84) and seizure disorder (0.75). Sensitivity estimates were low (< 0.50) for other neurological conditions, including TBI and MS.

Analyses

We conducted descriptive analyses to examine the distribution of sociodemographic, psychosocial and health characteristics by the following comparison groups: "Dementia," "Stroke," "Other Neurological Condition" (presence of 1+ of the priority neurological conditions – MS, PD, TBI, HD, MD, CP, SCI, ALS, epilepsy) and "Cognitively Intact Controls" (clients without any of the selected 11 neurological conditions and a CPS score of 0 or 1).

Descriptive analyses were also performed comparing the characteristics of those with dementia alone to those with dementia and other documented neurological conditions (i.e. dementia with stroke only, dementia with PD only, dementia with PD and stroke only, dementia with TBI only). These comparison groups excluded clients with any of the other selected neurological conditions.

Results

Clients with dementia vs. stroke, other neurological conditions and cognitively intact controls (Tables 1A & 1B)

Our analysis included 104 802 clients (21.5%) with a diagnosis of dementia, 85 579 (17.5%) with stroke and 23 007 (4.7%) with one or more of the other priority neurological conditions (20 972 (4.3%) clients had a recorded diagnosis of both dementia and stroke). Almost half (n = 236 763; 48.5%) were in the cognitively intact control group. Excluded from the analyses were 59 089 clients (12.1%) with meaningful cognitive impairment (CPS 2+) but no priority neurological diagnosis, and 22 clients with missing CPS values.

Compared with the stroke and other neurological groups, clients with dementia were more likely to be female (63.7%) and older, with a mean age (standard deviation) of 83.2 (7.6) years. Across all groups, women were significantly less likely to be married than were men. Relatively few clients reported making economic trade-offs, and this was less common for dementia clients than for those with other neurological conditions. Compared with controls, clients across all three diagnostic groups were more likely to co-reside with their primary caregiver. Among those with dementia or stroke this caregiver was most often a child or child-in-law. Clients with dementia were more likely to have reported conflicts with others, a distressed caregiver, moderate to severe cognitive impairment, significant difficulties with Instrumental Activities of Daily Living (IADLs), and some impairment in ADLs (Table 1A).

Dementia clients were more likely to have some level of health instability and considerably higher levels of aggression, wandering, anxiety and hallucinations/delusions than all other groups (Table 1B). These findings help to explain the significantly greater proportion of dementia clients with high to very high MAPLe scores (Figure 1) and distressed caregivers. For all sub-groups, the proportion of clients with a distressed caregiver increased with increasing MAPLe scores (Figure 2). However, for all levels of MAPLe, the proportion of clients with a distressed caregiver was relatively higher for those with dementia than those in the comparison groups. Clinically important depressive symptoms were slightly more common in dementia clients than the other groups, though depression and anxiety were not uncommon in clients with other neurological conditions or stroke.

For all groups, the most common comorbid diagnoses were cardiovascular diseases, arthritis and diabetes. Most clinical diagnoses were less prevalent in clients with dementia or other neurological conditions relative to clients in the stroke or control groups. All three neurological diagnostic groups showed a lower prevalence of cancer. A recent fall, unsteady gait and pressure ulcers were more common in clients with other neurological conditions and then in those with stroke. Relative to cognitively intact clients, swallowing problems were more

TABLE 1A

Sociodemographic, psychosocial and functional characteristics among home care clients by diagnostic group, Ontario, Canada, 2003–2010

Characteristic	Cognitively intact[b] (n = 236 763)	Other neurological conditions[c] (n = 23 007)	Stroke (n = 85 579)	Dementia (n = 104 802)
	Percent (95% confidence interval)[a]			
Sociodemographic				
Mean age (SD), years	77.1 (11.4)	73.3 (11.8)	80.5 (9.5)	83.2 (7.6)
85+	27.8 (27.6–28.0)	17.2 (16.7–17.7)	35.1 (34.8–35.4)	43.6 (43.3–43.9)
Sex				
Female	65.1 (64.9–65.3)	55.3 (54.6–55.9)	57.5 (57.2–57.9)	63.7 (63.4–63.9)
Married				
Female	30.1 (29.9–30.3)	37.8 (36.9–38.6)	27.1 (26.7–27.5)	26.9 (26.6–27.2)
Male	59.9 (59.5–60.2)	61.5 (60.6–62.5)	63.9 (63.4–64.4)	65.5 (65.1–66.0)
Widowed				
Female	54.3 (54.1–54.6)	39.3 (38.5–40.1)	61.6 (61.2–62.1)	64.1 (63.7–64.5)
Male	21.7 (21.4–22.0)	14.9 (14.2–15.6)	22.0 (21.6–22.5)	24.1 (23.6–24.5)
Made economic trade-offs	1.9 (1.9–2.0)	2.7 (2.5–2.9)	1.8 (1.8–1.9)	1.0 (0.9–1.1)
Psychosocial				
Co-resides with primary caregiver				
No	46.3 (46.1–46.5)	37.2 (36.5–37.8)	40.7 (40.4–41.1)	42.9 (42.6–43.2)
Yes	50.3 (50.1–50.5)	59.5 (58.9–60.2)	57.6 (57.2–57.9)	56.0 (55.7–56.3)
No such helper	3.4 (3.3–3.5)	3.3 (3.1–3.6)	1.7 (1.6–1.8)	1.1 (1.0–1.1)
Primary caregiver				
Child or child-in-law	46.5 (46.3–46.7)	34.0 (33.3–34.6)	49.9 (49.6–50.2)	53.7 (53.4–54.0)
Spouse	32.2 (32.1–32.4)	42.3 (41.7–43.0)	35.3 (35.0–35.6)	33.7 (33.5–34.0)
Other relative	9.9 (9.8–10.0)	12.5 (12.1–13.0)	7.7 (7.6–7.9)	7.6 (7.4–7.7)
Friend/neighbour	7.9 (7.8–8.0)	7.8 (7.5–8.2)	5.4 (5.2–5.5)	3.9 (3.8–4.0)
Conflicts with others	10.1 (10.0–10.2)	12.4 (12.0–12.8)	13.1 (12.9–13.3)	17.2 (17.0–17.5)
Caregiver distressed	10.0 (9.9–10.1)	21.6 (21.1–22.1)	22.6 (22.3–22.9)	34.9 (34.6–35.2)
Functional				
CPS score				
Intact (0–1)	100.0	63.2 (62.5–63.8)	48.0 (47.7–48.4)	7.4 (7.3–7.6)
Mild impairment (2)	—	28.1 (27.5–28.7)	32.7 (32.4–33.0)	44.6 (44.3–44.9)
Moderate impairment (3–4)	—	5.8 (5.5–6.1)	12.2 (12.0–12.4)	29.3 (29.0–29.5)
Severe impairment (5–6)	—	2.9 (2.7–3.2)	7.1 (6.9–7.3)	18.7 (18.4–18.9)
ADL score				
Independent (0)	78.4 (78.2–78.6)	46.9 (46.3–47.5)	50.2 (49.9–50.5)	37.2 (36.9–37.5)
Supervision/limited (1–2)	15.4 (15.2–15.5)	26.9 (26.3–27.4)	28.0 (27.7–28.3)	37.9 (37.6–38.2)
Extensive (3–4)	4.9 (4.9–5.0)	17.9 (17.4–18.4)	15.3 (15.0–15.5)	18.8 (18.5–19.0)
Dependence (5–6)	1.3 (1.2–1.3)	8.3 (8.0–8.7)	6.5 (6.4–6.7)	6.1 (6.0–6.3)
IADL score[d]				
0	15.2 (15.1–15.3)	4.4 (4.1–4.6)	3.8 (3.7–4.0)	0.7 (0.6–0.7)
1–2	41.1 (40.9–41.3)	23.3 (22.7–23.8)	17.7 (17.5–18.0)	4.4 (4.3–4.5)
3–4	43.7 (43.5–43.9)	72.4 (71.8–72.9)	78.4 (78.1–78.7)	95.0 (94.8–95.1)

Abbreviations: CPS, Cognitive Performance Score; IADL, Instrumental Activity of Daily Living; RAI-HC, Resident Assessment Instrument-Home Care; SD, standard deviation.

[a] Except where otherwise indicated.

[b] Clients without any of the 11 selected neurological conditions and CPS of 0 or 1.

[c] Clients with ≥ 1 of the other selected neurological conditions (excluding dementia and stroke).

[d] Summary of the following IADLs on the RAI-HC: meal preparation, managing finances, managing medications and transportation; represents # of activities where client experiencing some/greater difficulty performing on own.

TABLE 1B
Health characteristics among home care clients by diagnostic group, Ontario, Canada, 2003–2010

Characteristic	Percent (95% confidence interval)[a]			
	Cognitively intact[b] (n = 236 763)	Other neurological conditions[c] (n = 23 007)	Stroke (n = 85 579)	Dementia (n = 104 802)
Health Instability (CHESS)				
None (0)	32.0 (31.8–32.1)	30.7 (30.1–31.3)	29.6 (29.3–30.0)	25.6 (25.3–25.8)
Mild (1–2)	55.7 (55.5–55.9)	57.6 (57.0–58.3)	55.6 (55.3–56.0)	58.4 (58.1–58.7)
Moderate/High (3+)	12.3 (12.2–12.5)	11.7 (11.3–12.1)	14.7 (14.5–15.0)	16.1 (15.8–16.3)
MAPLe scale				
Stable (1)	38.3 (38.1–38.5)	13.1 (12.7–13.5)	12.0 (11.8–12.2)	1.6 (1.5–1.6)
Mild/Moderate (2–3)	53.1 (52.9–53.3)	46.9 (46.3–47.6)	40.4 (40.0–40.7)	16.3 (16.0–16.5)
High/Very high (4–5)	8.6 (8.5–8.7)	39.9 (39.3–40.6)	47.6 (47.3–48.0)	82.2 (81.9–82.4)
DRS				
Yes (3+)	12.0 (11.8–12.1)	17.6 (17.1–18.1)	16.3 (16.1–16.6)	19.9 (19.7–20.1)
Aggressive Behaviour Score[d]				
None (0)	98.6 (98.5–98.6)	94.5 (94.2–94.8)	90.2 (90.0–90.4)	73.3 (73.0–73.5)
Mild/Moderate (1)	1.2 (1.2–1.3)	4.0 (3.8–4.3)	6.7 (6.6–6.9)	16.7 (16.5–16.9)
Severe (2+)	0.2 (0.2–0.2)	1.5 (1.3–1.6)	3.1 (3.0–3.2)	10.0 (9.8–10.2)
Behavioural symptoms				
Wandering	0.1 (0.0–0.1)	1.1 (1.0–1.3)	3.1 (3.0–3.2)	13.0 (12.8–13.2)
Verbally abusive	0.7 (0.6–0.7)	2.6 (2.4–2.8)	4.5 (4.4–4.6)	11.4 (11.2–11.6)
Physically abusive	0.0 (0.0–0.1)	0.5 (0.4–0.6)	1.2 (1.2–1.3)	3.9 (3.8–4.1)
Socially inappropriate/disruptive	0.2 (0.1–0.2)	1.3 (1.2–1.5)	2.2 (2.1–2.3)	6.9 (6.8–7.1)
Resists care	0.8 (0.8–0.9)	3.1 (2.9–3.3)	6.3 (6.2–6.5)	19.1 (18.8–19.3)
Mental Health				
Any anxiety symptoms	10.3 (10.2–10.4)	15.6 (15.1–16.0)	14.8 (14.6–15.0)	22.6 (22.4–22.9)
Hallucinations or delusions	0.6 (0.6–0.7)	4.3 (4.0–4.6)	3.9 (3.8–4.0)	11.3 (11.1–11.4)
Diagnoses				
Arthritis	51.6 (51.4–51.8)	42.0 (41.3–42.6)	49.9 (49.5–50.2)	43.6 (43.3–43.9)
Cancer (past 5 years)	25.6 (25.4–25.7)	9.8 (9.4–10.2)	12.1 (11.8–12.3)	8.5 (8.4–8.7)
Diabetes	25.9 (25.7–26.0)	17.9 (17.4–18.4)	30.5 (30.2–30.8)	19.9 (19.7–20.2)
Emphysema/COPD/asthma	19.4 (19.3–19.6)	12.4 (11.9–12.8)	16.9 (16.6–17.2)	11.6 (11.4–11.8)
Heart failure	13.9 (13.7–14.0)	7.3 (7.0–7.7)	16.1 (15.8–16.3)	10.2 (10.0–10.3)
Other CVD[e]	66.8 (66.6–67.0)	50.5 (49.9–51.2)	78.9 (78.6–79.2)	63.5 (63.2–63.8)
Health Issues				
Fell < 90 days	27.1 (26.9–27.3)	45.3 (44.6–45.9)	37.1 (36.8–37.5)	35.1 (34.8–35.4)
Unsteady gait	52.5 (52.3–52.7)	74.7 (74.1–75.2)	71.6 (71.3–71.9)	59.0 (58.7–59.3)
Pressure ulcers	4.4 (4.3–4.5)	6.4 (6.1–6.7)	4.9 (4.7–5.0)	3.7 (3.6–3.8)
Swallowing problems	10.6 (10.4–10.7)	20.6 (20.1–21.2)	24.4 (24.1–24.7)	32.2 (31.9–32.5)
≥ 1 ED visits < 90 days	21.0 (20.9–21.2)	19.5 (19.0–20.0)	20.9 (20.7–21.2)	17.5 (17.2–17.7)
≥ 1 hospital admissions < 90 days	36.3 (36.1–36.5)	23.3 (22.8–23.9)	31.2 (30.9–31.5)	18.2 (18.0–18.5)
9+ medications	46.2 (46.0–46.4)	47.1 (46.4–47.7)	55.5 (55.1–55.8)	40.3 (40.0–40.6)

Continued on the following page

prevalent in the three neurological diagnostic groups, particularly in clients with dementia.

Dementia clients were less likely than the other groups to have experienced one or more ED visits or hospitalizations in the previous 90 days or to use nine or more medications. Conversely, they were more likely than the other groups to be taking an antipsychotic/neuroleptic. Other psychotropic drug classes were more commonly used by clients with other neurological conditions. Multiple medication use (9+) was most common in stroke clients, presumably due to their relatively higher levels of comorbid illnesses (e.g. diabetes, cardiovascular diseases [CVDs]).

TABLE 1B (continued)
Health characteristics among home care clients by diagnostic group, Ontario, Canada, 2003–2010

Characteristic	Percent (95% confidence interval)[a]			
	Cognitively intact[b] (n = 236 763)	Other neurological conditions[c] (n = 23 007)	Stroke (n = 85 579)	Dementia (n = 104 802)
Psychotropic drug use				
Antipsychotic/neuroleptic	3.8 (3.7–3.8)	11.2 (10.8–11.6)	9.8 (9.6–10.0)	22.5 (22.2–22.8)
Anxiolytic	17.0 (16.8–17.1)	20.7 (20.2–21.2)	16.7 (16.5–17.0)	14.8 (14.6–15.1)
Antidepressant	18.1 (17.9–18.3)	30.1 (29.5–30.6)	27.1 (26.8–27.4)	28.4 (28.1–28.6)
Hypnotic	14.2 (14.1–14.4)	15.6 (15.1–16.1)	14.3 (14.1–14.5)	11.8 (11.6–12.0)
Any dementia medication	0.9 (0.9–1.0)	5.0 (4.7–5.3)	13.0 (12.8–13.2)	49.3 (49.0–49.6)

Abbreviations: CHESS, Changes in Health, End-stage Disease, and Signs and Symptoms; COPD, chronic obstructive pulmonary disease; CPS, Cognitive Performance Score; CVD, cardiovascular disease; DRS, Depression Rating Scale; ED, emergency department; MAPLe, Method for Assigning Priority Levels; RAI-HC, Resident Assessment Instrument-Home Care.

[a] Except where otherwise indicated.

[b] Clients without any of the 11 selected neurological conditions and CPS of 0 or 1.

[c] Clients with ≥ 1 of the other selected neurological conditions (excluding dementia and stroke).

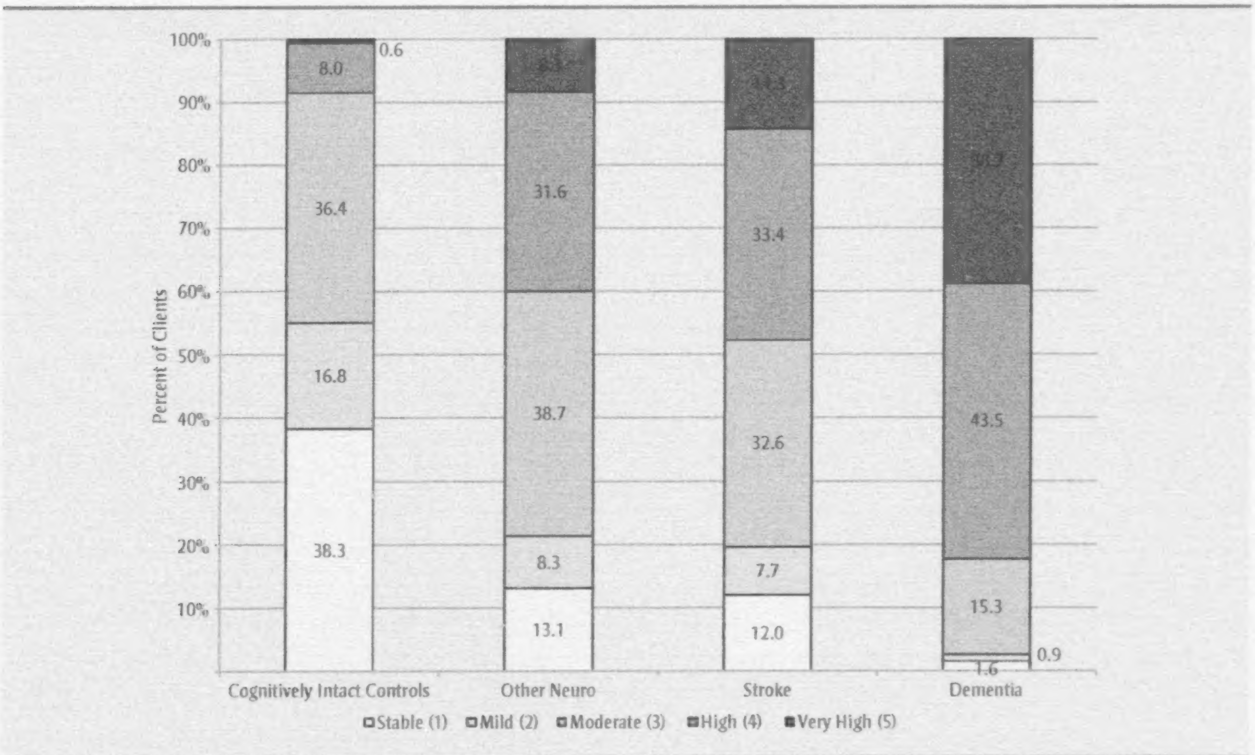
[d] Summary scale of the following behaviours on the RAI-HC: verbally abusive, physically abusive, socially inappropriate/disruptive or resists care; higher scores indicate greater number and frequency of behavioural issues.

[e] Includes the following cardiovascular conditions listed on the RAI-HC: coronary artery disease, hypertension, irregularly irregular pulse and/or peripheral vascular disease.

Approximately half of dementia clients used a dementia medication.

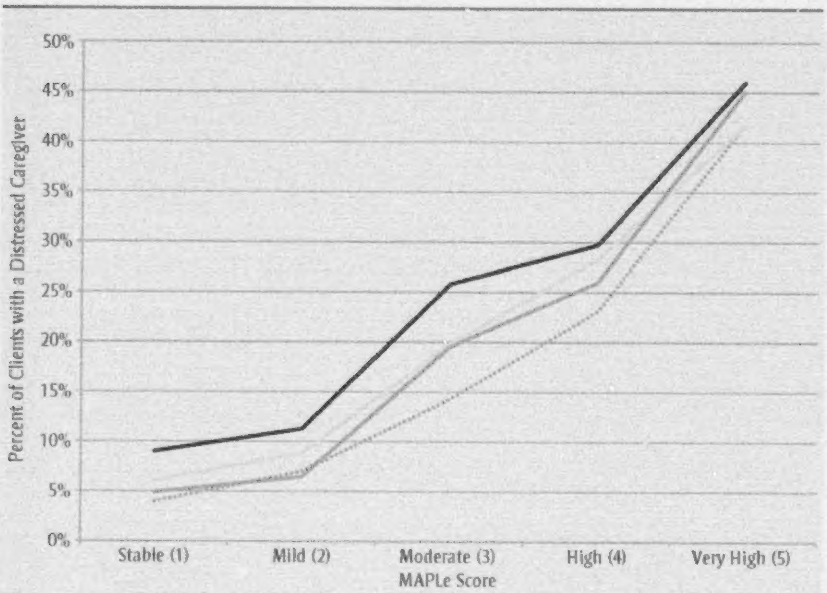
Compared with cognitively intact clients, those with dementia, stroke or other neurological conditions were more likely to have received care from home health care aides (61%-66% vs. 48%) and homemaking services (42% vs. 31%) in the previous seven days but were less likely to have received care from a visiting registered nurse (25%-28% vs. 40%). Clients with dementia were also less likely than all other groups to have received physical therapy (7% vs. 13%-15%) or

FIGURE 1
Distribution of MAPLe levels by Diagnostic Comparison Group



Abbreviation: MAPLe, Method for Assigning Priority Levels.

FIGURE 2
Percentage of Clients with a Distressed Caregiver by MAPLe level and Diagnostic Comparison Group



Abbreviation: MAPLe, Method for Assigning Priority Levels.

occupational therapy (8% vs. 10%–16%) in the previous week (data not shown; details available on request).

Clients with dementia alone vs. dementia with other neurological conditions (Tables 2A & 2B)

The dementia cohort included 77 670 (74.1%) clients with dementia alone, 19 061 (18.2%) with co-existing stroke, 4480 (4.3%) with PD, 1182 (1.1%) with both PD and stroke, and 763 (0.7%) with TBI (Table 2A). There were 1646 (1.6%) clients with dementia and some other combination(s) with selected neurological conditions that were rare and thus not presented.

Dementia clients with co-existing PD (with or without stroke) or TBI were generally younger and more likely to be male compared with the other two groups. This age/sex distribution likely explains the relatively higher proportion of married clients (with an available co-residing spousal caregiver) in the groups with dementia and PD (with or without stroke). Dementia clients with TBI were more likely than the other groups to have reported conflicts with others, and along with those with PD (with or without stroke), were more likely to have a distressed caregiver. Dementia clients with co-existing PD *and* stroke were more likely to exhibit higher levels of cognitive impairment and ADL dependence than the other groups.

Moderate to high health instability was slightly more common in dementia clients with stroke (including stroke/PD) or TBI (Table 2B). All groups showed similar proportions at high/very high MAPLe levels and with clinically important depressive symptoms. Aggressive behaviours were less prevalent in dementia clients with PD (with or without stroke) and more common in those with co-existing TBI. Anxiety symptoms were slightly more common in dementia clients with TBI, whereas hallucinations/delusions were more prevalent in dementia clients with PD.

Generally, various comorbid illnesses (e.g. arthritis, diabetes, CVDs) were more common in dementia clients with co-existing stroke and less common in those with co-existing PD only. A recent fall, unsteady gait and pressure ulcers were more common in dementia clients with co-existing PD. Overall, compared with dementia-only clients, all four groups with co-existing neurological conditions showed a higher prevalence of recent falls, unsteady gait and problems with swallowing (the latter were especially common in those with dementia, PD *and* stroke). A recent ED visit or hospitalization was also more common in the four groups with a co-existing neurological condition relative to the dementia-only group. A recent hospitalization was especially common in dementia clients with stroke (including stroke/PD) or TBI. The use of nine or more medications was less common in those with dementia alone or with TBI, and more common in those with co-existing stroke or PD (particularly stroke with PD).

Dementia clients with PD (with or without stroke) generally showed higher use of antipsychotic/neuroleptic and antidepressant medications compared with the other groups. Clients with PD (no stroke) and with dementia alone were more likely than the other groups to be using a cholinesterase inhibitor and/or memantine, whereas those with TBI or stroke (no PD) showed the lowest use.

Discussion

Findings from this population-based study of home care clients in Ontario highlight the substantial psychosocial, functional and mental health needs of people with dementia who live in the community. Our work expands on previous literature by providing a recent and comprehensive profile of the key domains relevant to the care, quality of life and health outcomes of this growing population. As a further contribution, we provide estimates of the prevalence of common co-existing neurological conditions and the associated complexity of health and care planning needs imposed by this comorbidity.

Clients with dementia vs. stroke, other neurological conditions and cognitively intact controls

Approximately 22% of Ontario long-stay home care clients (n = 104 802) had been

TABLE 2A
Sociodemographic, psychosocial and functional characteristics among home care clients with dementia (by co-existing neurological condition), Ontario, Canada, 2003–2010

Characteristic	Percent (95% confidence interval)[a]				
	Dementia only[b] (n = 77 670)	Dementia and stroke[c] (n = 19 061)	Dementia and PD[c] (n = 4480)	Dementia, PD and stroke[d] (n = 1182)	Dementia and TBI[c] (n = 763)
Sociodemographic					
Mean age (SD), years	83.5 (7.5)	83.3 (7.3)	80.6 (6.9)	81.7 (6.6)	80.1 (9.6)
85+	45.4 (45.1–45.8)	43.2 (42.5–43.9)	26.5 (25.2–27.8)	30.1 (27.5–32.7)	35.0 (31.6–38.4)
Sex					
Female	67.2 (66.9–67.6)	57.2 (56.4–57.9)	41.4 (40.0–42.8)	39.5 (36.7–42.3)	51.9 (48.3–55.5)
Married					
Male	63.0 (62.4–63.6)	68.6 (67.6–69.6)	77.6 (76.0–79.2)	78.0 (75.0–81.1)	61.9 (56.9–66.8)
Female	26.4 (26.0–26.7)	26.6 (25.8–27.5)	38.7 (36.5–40.9)	30.6 (26.4–34.8)	29.8 (25.3–34.3)
Made economic trade-offs	0.9 (0.8–1.0)	1.3 (1.1–1.4)	1.3 (0.9–1.6)	1.1 (0.5–1.7)	2.1 (1.1–3.1)
Psychosocial					
Co-resides with primary caregiver					
No	45.5 (45.1–45.8)	37.1 (36.4–37.8)	29.5 (28.2–30.9)	25.5 (23.0–28.0)	43.6 (40.0–47.1)
Yes	53.4 (53.0–53.7)	62.1 (61.4–62.8)	69.8 (68.4–71.1)	74.2 (71.7–76.7)	54.7 (51.2–58.3)
No such helper	1.1 (1.1–1.2)	0.8 (0.7–1.0)	0.7 (0.5–1.0)	0.3 (0.0–0.7)	1.7 (0.8–2.6)
Primary caregiver					
Child or child-in-law	55.4 (55.1–55.8)	52.4 (51.7–53.2)	38.0 (36.5–39.4)	42.6 (39.8–45.5)	46.8 (43.2–50.3)
Spouse	31.2 (30.8–31.5)	37.6 (36.9–38.3)	53.9 (52.4–55.3)	51.4 (48.6–54.3)	37.4 (33.9–40.8)
Other relative	8.1 (7.9–8.3)	6.0 (5.6–6.3)	4.8 (4.2–5.4)	3.7 (2.6–4.8)	9.6 (7.5–11.7)
Friend/neighbour	4.1 (4.0–4.3)	3.2 (2.9–3.4)	2.6 (2.1–3.1)	1.9 (1.1–2.6)	4.5 (3.0–5.9)
Conflicts with others	17.4 (17.2–17.7)	17.1 (16.6–17.6)	14.5 (13.5–15.5)	14.0 (12.0–15.9)	21.7 (18.7–24.6)
Caregiver distressed	34.4 (34.1–34.8)	35.2 (34.5–35.8)	39.3 (37.9–40.7)	39.5 (36.7–42.3)	40.4 (36.9–43.9)
Functional					
CPS score					
Intact (0–1)	7.5 (7.3–7.7)	7.0 (6.7–7.4)	8.0 (7.2–8.8)	5.8 (4.5–7.2)	6.7 (4.9–8.5)
Mild impairment (2)	45.3 (44.9–45.6)	43.5 (42.8–44.2)	42.7 (41.3–44.2)	37.3 (34.5–40.1)	40.4 (36.9–43.9)
Moderate impairment (3–4)	29.3 (29.0–29.6)	29.5 (28.9–30.2)	27.5 (26.1–28.8)	29.9 (27.3–32.5)	33.0 (29.7–36.4)
Severe impairment (5–6)	18.0 (17.7–18.2)	20.0 (19.4–20.6)	21.8 (20.6–23.0)	27.0 (24.5–29.5)	19.9 (17.1–22.8)
ADL score					
Independent (0)	39.9 (39.6–40.3)	31.8 (31.1–32.4)	21.0 (19.8–22.2)	17.5 (15.3–19.7)	36.8 (33.4–40.3)
Supervision/Limited (1–2)	38.2 (37.9–38.6)	37.0 (36.3–37.7)	37.2 (35.7–38.6)	34.1 (31.4–36.8)	37.6 (34.2–41.1)
Extensive (3–4)	17.1 (16.8–17.3)	21.8 (21.2–22.4)	30.8 (29.5–32.2)	30.2 (27.6–32.8)	20.1 (17.2–22.9)
Dependence (5–6)	4.8 (4.6–4.9)	9.4 (9.0–9.8)	11.1 (10.1–12.0)	18.2 (16.0–20.4)	5.5 (3.9–7.1)
IADL score[e]					
0	0.8 (0.7–0.8)	0.4 (0.3–0.5)	0.2 (0.1–0.4)	0.3 (0.0–0.5)	0.7 (0.1–1.2)
1–2	4.8 (4.6–4.9)	3.3 (3.1–3.6)	2.5 (2.1–3.0)	1.4 (0.8–2.1)	5.5 (3.9–7.1)
3–4	94.5 (94.3–94.6)	96.2 (96.0–96.5)	97.2 (96.8–97.7)	98.3 (97.6–99.0)	93.8 (92.1–95.5)

Abbreviations: ADL, Activities of Daily Living; CPS, Cognitive Performance Score; IADL, Instrumental Activities of Daily Living; PD, Parkinson disease/Parkinsonism; SD, standard deviation; TBI, traumatic brain injury.

[a] Except where otherwise indicated.

[b] Excludes the other 10 selected neurological conditions.

[c] Excludes the other 9 selected neurological conditions.

[d] Excludes the other 8 selected neurological conditions.

[e] Summary scale of the following IADLs on the RAI-HC: meal preparation, managing finances, managing medications and transportation; represents # of activities where client experiencing some/greater difficulty performing on own.

TABLE 2B
Health characteristics among home care clients with dementia (by co-existing neurological condition), Ontario, Canada, 2003–2010

Characteristic	Percent (95% confidence interval)[a]				
	Dementia only[b] (n = 77 670)	Dementia and stroke[c] (n = 19 061)	Dementia and PD[c] (n = 4480)	Dementia, PD and stroke[d] (n = 1182)	Dementia and TBI[c] (n = 763)
Health instability (CHESS)					
None (0)	25.8 (25.5–26.1)	25.1 (24.5–25.7)	23.1 (21.9–24.4)	22.3 (19.9–24.6)	25.0 (22.0–28.1)
Mild (1–2)	58.7 (58.3–59.0)	56.8 (56.1–57.5)	60.8 (59.3–62.2)	58.5 (55.6–61.3)	54.1 (50.6–57.7)
Moderate/High (3+)	15.5 (15.2–15.7)	18.1 (17.5–18.6)	16.1 (15.0–17.2)	19.3 (17.0–21.5)	20.8 (18.0–23.7)
MAPLe Scale					
Stable (1)	1.7 (1.6–1.8)	1.1 (0.9–1.2)	0.8 (0.6–1.1)	0.7 (0.2–1.1)	1.6 (0.7–2.5)
Mild/Moderate (2–3)	15.9 (15.6–16.2)	17.2 (16.7–17.8)	19.1 (17.9–20.2)	16.8 (14.6–18.9)	12.2 (9.9–14.5)
High/Very high (4–5)	82.4 (82.1–82.6)	81.7 (81.1–82.2)	80.1 (78.9–81.3)	82.6 (80.4–84.7)	86.2 (83.8–88.7)
DRS					
Yes (3+)	19.7 (19.4–19.9)	20.0 (19.4–20.6)	21.6 (20.4–22.8)	22.8 (20.4–25.2)	24.9 (21.9–28.0)
Aggressive Behaviour Score[e]					
None (0)	72.5 (72.2–72.8)	74.7 (74.1–75.4)	78.8 (77.6–80.0)	79.1 (76.8–81.4)	68.3 (65.0–71.6)
Mild/moderate (1)	17.1 (16.9–17.4)	16.1 (15.5–16.6)	14.0 (13.0–15.0)	13.5 (11.6–15.5)	17.0 (14.3–19.6)
Severe (2+)	10.4 (10.2–10.6)	9.2 (8.8–9.6)	7.3 (6.5–8.0)	7.4 (5.9–8.9)	14.7 (12.2–17.2)
Behavioural symptoms					
Wandering	13.8 (13.6–14.1)	10.4 (10.0–10.8)	10.5 (9.6–11.4)	9.0 (7.3–10.6)	17.6 (14.9–20.3)
Verbally abusive	11.5 (11.3–11.8)	11.3 (10.8–11.7)	8.4 (7.6–9.2)	8.9 (7.3–10.5)	16.1 (13.5–18.8)
Physically abusive	4.0 (3.8–4.1)	3.8 (3.5–4.0)	3.5 (2.9–4.0)	3.8 (2.7–4.9)	6.6 (4.8–8.3)
Socially inappropriate/disruptive	7.1 (7.0–7.3)	6.4 (6.1–6.8)	5.1 (4.4–5.7)	5.8 (4.4–7.1)	9.7 (7.6–11.8)
Resists care	19.9 (19.6–20.2)	17.2 (16.6–17.7)	14.7 (13.6–15.7)	13.6 (11.7–15.6)	22.5 (19.5–25.4)
Mental health					
Any anxiety symptoms	22.9 (22.6–23.2)	21.5 (20.9–22.0)	22.9 (21.7–24.2)	21.1 (18.7–23.4)	26.8 (23.6–29.9)
Hallucinations or delusions	11.0 (10.8–11.2)	9.9 (9.5–10.3)	20.0 (18.9–21.2)	16.6 (14.5–18.7)	14.3 (11.8–16.8)
Diagnoses					
Arthritis	43.1 (42.7–43.4)	46.7 (46.0–47.4)	38.9 (37.4–40.3)	48.6 (45.7–51.4)	45.1 (41.5–48.6)
Cancer (past 5 years)	8.3 (8.1–8.5)	9.5 (9.1–10.0)	8.0 (7.2–8.8)	8.6 (7.0–10.2)	8.1 (6.2–10.1)
Diabetes	18.6 (18.3–18.9)	25.7 (25.0–26.3)	17.0 (15.9–18.1)	24.1 (21.7–26.6)	21.5 (18.6–24.4)
Emphysema/COPD/asthma	11.2 (11.0–11.4)	13.5 (13.0–14.0)	9.2 (8.3–10.0)	11.5 (9.7–13.3)	13.5 (11.1–15.9)
Heart failure	9.4 (9.2–9.6)	13.9 (13.5–14.4)	6.7 (6.0–7.4)	12.2 (10.3–14.1)	11.3 (9.0–13.5)
Other CVD[f]	61.1 (60.8–61.4)	75.9 (75.3–76.5)	51.1 (49.7–52.6)	71.7 (69.2–74.3)	62.4 (58.9–65.8)
Health issues					
Fell < 90 days	32.8 (32.4–33.1)	38.4 (37.7–39.1)	52.2 (50.7–53.6)	48.6 (45.8–51.5)	47.7 (44.2–51.3)
Unsteady gait	54.6 (54.2–54.9)	69.1 (68.4–69.7)	81.0 (79.8–82.1)	82.2 (80.1–84.4)	68.4 (65.1–71.7)
Pressure ulcers	3.2 (3.0–3.3)	4.7 (4.4–5.0)	6.6 (5.9–7.3)	8.3 (6.7–9.9)	3.1 (1.9–4.4)
Swallowing problems	29.9 (29.6–30.3)	38.4 (37.7-39.1)	37.5 (36.1–38.9)	46.6 (43.8–49.5)	35.4 (32.0–38.8)
≥ 1 ED visits < 90 days	16.6 (16.3–16.8)	19.9 (19.4–20.5)	19.0 (17.9–20.2)	19.5 (17.3–21.8)	23.3 (20.3–26.3)
≥ 1 hospital admissions < 90 days	16.4 (16.1–16.6)	24.6 (23.9–25.2)	18.7 (17.5–19.8)	24.4 (21.9–26.8)	24.8 (21.7–27.8)
9+ Medications	37.1 (36.8–37.5)	50.1 (49.3–50.8)	47.1 (45.6–48.6)	56.7 (53.9–59.5)	38.5 (35.1–42.0)
Psychotropic drug use					
Antipsychotic/neuroleptic	22.4 (22.1–22.7)	21.0 (20.4–21.6)	27.0 (25.7–28.3)	25.8 (23.3–28.3)	25.0 (22.0–28.1)
Anxiolytic	14.5 (14.2–14.7)	15.4 (14.9–15.9)	16.9 (15.8–17.9)	16.6 (14.5–18.7)	16.3 (13.6–18.9)
Antidepressant	27.2 (26.9–27.5)	31.1 (30.5–31.8)	33.2 (31.9–34.6)	34.6 (31.9–37.3)	30.0 (26.8–33.3)

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TABLE 2B (continued)
Health characteristics among home care clients with dementia (by co-existing neurological condition), Ontario, Canada, 2003–2010

Characteristic	Percent (95% confidence interval)[a]				
	Dementia only[b] (n = 77 670)	Dementia and stroke[c] (n = 19 061)	Dementia and PD[c] (n = 4480)	Dementia, PD and stroke[d] (n = 1182)	Dementia and TBI[c] (n = 763)
Hypnotic	11.3 (11.1–11.5)	13.0 (12.5–13.5)	13.0 (12.1–14.0)	13.2 (11.3–15.1)	16.1 (13.5–18.7)
Any dementia medication	51.4 (51.0–51.7)	41.7 (41.0–42.4)	53.9 (52.5–55.4)	46.4 (43.5–49.2)	38.8 (35.3–42.3)

Abbreviations: CHESS, Changes in Health, End-stage Disease, and Signs and Symptoms; COPD, chronic obstructive pulmonary disease; CVD, cardiovascular disease; DRS, Depression Rating Scale; ED, emergency department; MAPLe, Method for Assigning Priority Levels; PD, Parkinson disease/Parkinsonism; RAI-HC, Resident Assessment Instrument-Home Care; SD, standard deviation; TBI, traumatic brain injury.

[a] Except where otherwise indicated.

[b] Excludes the other 10 selected neurological conditions.

[c] Excludes the other 9 selected neurological conditions.

[d] Excludes the other 8 selected neurological conditions.

[e] Summary scale of the following behaviours on the RAI-HC: verbally abusive, physically abusive, socially inappropriate/disruptive or resists care; higher scores indicate greater number and frequency of behavioural issues.

[f] Includes the following cardiovascular conditions listed on the RAI-HC: coronary artery disease, hypertension, irregularly irregular pulse or peripheral vascular disease.

diagnosed as having dementia. A common profile was that of an older (>75 years) widowed woman supported by a child (or child-in-law) as her primary caregiver. However, in about one-third of dementia clients, the primary caregiver was a spouse who was likely of the same age or older and likely soon facing challenges to his/her own health and social well-being. Approximately 43% of dementia clients (and 50% of those with cognitive impairment but no diagnosis) did not co-reside with their primary caregiver. The lack of a close or well-informed advocate available to monitor and communicate their needs in a timely manner may lead to an increased risk of fragmented or sub-optimal care and more rapid disease progression.[40,41]

Almost half of dementia clients had moderate to severe cognitive impairment (CPS score 3+) and almost all experienced some or great difficulty with multiple IADLs. As informal and formal care costs increase with dementia severity,[3,6,42] this finding has important implications for family caregivers, health care providers and policy makers. Consistent with their level of cognitive impairment, dementia clients showed a significantly higher prevalence of aggression, anxiety, wandering and hallucinations/delusions than other diagnostic groups. They were also more likely to exhibit clinically important depressive symptoms. In their examination of 2005 Canadian Community Health Survey participants aged 55 years and over, Nabalamba and Patten[43] also observed higher levels of mood (19.5%) and anxiety (16.3%) disorders in people with dementia. The clustering of cognitive, behavioural and psychiatric issues evident in dementia clients helps to explain the greater likelihood of caregiver distress[17] (approximately 35% of family caregivers in our study) as well as clients' increased risk of institutionalization[17,44] and higher care costs.[42,45] Specifically, 82% of clients with dementia displayed high to very high MAPLe scores indicating an imminent risk for transition to a higher level of care.

Clients with dementia (and those with other neurological conditions) showed a lower prevalence of several chronic conditions (including cardiovascular diseases, arthritis, diabetes, COPD and cancer) and lower levels of recent health service use (e.g. emergency room visits or hospitalizations in the previous 3 months and use of 9+ medications). While earlier research reported people with dementia (particularly those with Alzheimer disease) as being relatively healthier,[46,47] recent findings have been inconsistent.[45,48] The one exception is the lower prevalence of cancer consistently noted for those with dementia and other neurological conditions.[49] These inconsistencies likely reflect variations across investigations in study design and samples (e.g. sociodemographic characteristics, dementia severity and sub-types examined) and in the diagnostic and clinical health measures employed. Several studies have reported higher rates of comorbid health conditions, medication and health service use for those with vascular dementia (as compared with Alzheimer disease).[46,48] Our findings for dementia clients with co-existing stroke (Table 2B) are consistent with these reports. For some conditions, a lower prevalence may be the consequence of poorer detection and under-diagnosis in people with a dementia disorder.[48] Factors underlying this poorer recognition may include the atypical presentation of some conditions and the under-reporting of symptoms in patients with dementia as well as the stigma associated with the diagnosis of dementia. Additional efforts to investigate this possibility and potential strategies for improved detection of existing comorbidities in patients with dementia are warranted.[50] It should also be noted that dementia clients were significantly more likely to experience swallowing difficulties and to use antipsychotic/neuroleptic medications, both of which represent risk factors for decline and hospitalization.[45,51]

Clients with dementia alone vs. dementia with other neurological conditions

Approximately one in four dementia clients had a co-existing neurological condition (specific to our targeted conditions), most often stroke and then PD and TBI. Others have documented the relatively common co-occurrence of dementia in people with stroke or with PD.[20,52] Clients documented as having all three conditions (dementia, PD and stroke) showed the greatest burden in terms of more severe cognitive and ADL impairment. Compared with dementia-only clients, all four groups with co-existing neurological conditions showed a higher prevalence of recent falls, unsteady gait, swallowing problems (with the latter present in almost 50% of those with dementia, PD *and* stroke) and recent health service use.

Dementia clients with selected co-existing neurological conditions were also found to exhibit unique sociodemographic and health profiles. Those with dementia and PD were more likely to be younger and male and consequently more likely to co-reside with a spousal caregiver. In dementia clients with PD or with TBI, approximately 40% were noted to have a distressed caregiver (compared with about 35% for the other groups). Yet the underlying factors possibly contributing to caregiver burden varied in these groups. For example, dementia clients with TBI were more likely than other groups to experience conflicts with others, aggressive behaviours, wandering and recent worsening of mood and/or behaviours. Conversely, those with PD were less likely to have behavioural issues or conflicts but more likely to exhibit hallucinations and/or delusions.

There was evidence of greater health instability (e.g. higher CHESS scores and recent hospital use) in dementia clients with co-existing stroke or TBI. Further, those with dementia and co-existing stroke showed a higher prevalence of common comorbid health conditions (including cardiovascular illness, diabetes and arthritis) and polypharmacy (9+ medications). Although less likely than others to exhibit these comorbid health conditions, dementia clients with PD were more likely to have a recent fall, unsteady gait and pressure ulcers. The variation in cholinesterase inhibitor and/or memantine use observed in dementia clients with co-existing neurological conditions is intriguing and has been more fully examined in a separate publication.[53]

The unique care needs observed for particular dementia sub-groups illustrate the importance of tailored and co-ordinated home care services.[13] For example, further educational resources and behavioural management strategies may be a priority for dementia clients with TBI (and their caregivers) whereas dementia clients with PD may have a greater need for fall prevention strategies and rehabilitation services and dementia clients with co-existing stroke will need enhanced chronic disease management.

Important strengths of our study include the examination of a large population-based sample of older home care clients (allowing for greater precision in estimates, stratification by diagnostic subgroups and generalizability) and the complete and comprehensive nature of the RAI-HC assessment data. However, some limitations should be noted. Despite evidence supporting the validity of diagnostic data on the RAI-HC (including dementia),[37-39] further validation work is required. In addition, the diagnostic and cognitive data captured on the RAI-HC does not permit a differentiation of dementia sub-type (an important predictor of care needs and service use). Approximately 12.1% of clients (without a recorded neurological diagnosis) had moderate to significant cognitive impairment, and a proportion in this group (particularly those with a CPS score of 4+) are likely to have had a dementia disorder. The potential for diagnostic misclassification may have resulted in a reduced ability to detect relevant differences in client characteristics across some of our comparison groups. The cross-sectional nature of our data and the absence of prospective data on actual health system and home care use also limits our ability to comment on the differential burden and unmet care needs associated with selected co-existing neurological conditions in dementia clients.

Conclusions

Our findings suggest that a significant proportion of clients currently living with dementia in the community may be close to the tipping point in terms of their continued ability to remain in their own homes. These data support the argument that more flexible and enhanced community-based and caregiver assistance programs may be needed to ensure continued client and caregiver well-being and quality of care.[13,54] Of critical importance for all dementia clients (given the burden of mood and anxiety disorders) is the immediate need for improved, co-ordinated and integrated psychiatric and mental health services (with intensive case management).[43] Care providers (including case managers, primary care physicians and family caregivers) may face numerous structural barriers in obtaining access to appropriate mental health specialists and services,[55] leading to an increased likelihood for delayed or inappropriate treatment and poor outcomes for community-dwelling seniors with dementia. Further work detailing the extent and consequences of unmet needs associated with co-existing mental health and neurological conditions in dementia is clearly warranted.

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Conflict of interest

None.

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Performance of administrative case definitions for comorbidity in multiple sclerosis in Manitoba and Nova Scotia

R. A. Marrie, MD, PhD (1, 2); J. D. Fisk, PhD (3, 4, 5); K. J. Stadnyk, MSc (5); H. Tremlett, PhD (6); C. Wolfson, PhD (7, 8); S. Warren, PhD (9); V. Bhan, MD (3, 5); B. N. Yu, MD, PhD (1, 2), for the CIHR Team in the Epidemiology and Impact of Comorbidity on Multiple Sclerosis

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Abstract

Introduction: As the population ages and the prevalence of comorbid conditions increases, the need for feasible, validated methods of comorbidity surveillance in chronic diseases such as multiple sclerosis (MS) increases.

Methods: Using kappa (κ) statistics, we evaluated the performance of administrative case definitions for comorbidities commonly observed in MS by comparing agreement between Manitoba (MB) administrative data and self-report (n = 606) and Nova Scotia (NS) administrative data and self-report (n = 1923).

Results: Agreement between the administrative definitions and self-report was substantial for hypertension (κ = 0.69 [NS], 0.76 [MB]) and diabetes (κ = 0.70 [NS], 0.66 [MB]); moderate for hyperlipidemia (κ = 0.53 [NS], 0.51 [MB]) and heart disease (κ = 0.42 [NS], 0.51 [MB]) and fair for anxiety (κ = 0.27 [NS], 0.26 [MB]). In NS, agreement was substantial for inflammatory bowel disease (κ = 0.71) and moderate for epilepsy (κ = 0.48).

Conclusion: Administrative definitions for commonly observed comorbidities in MS performed well in 2 distinct jurisdictions. This suggests that they could be used more broadly across Canada and in national studies.

Keywords: administrative data, validation, comorbidity, multiple sclerosis

Introduction

Comorbidities in many chronic diseases are associated with a broad range of adverse outcomes including increased disability, mortality and health care utilization.[1] For example, vascular comorbidities such as hypertension are associated with more rapid cognitive decline in people with Alzheimer disease.[2] Multiple sclerosis (MS) is a chronic neurological disease affecting more than 2 million people worldwide.[3] It has a high incidence and prevalence in Canada,[4] with annual incidence rates as high as 23.9 per 100 000 population[5] and an estimated crude prevalence of 240 per 100 000 population in 2000/2001.[6] Physical and mental comorbidities are common in people with MS. Comorbidities have been associated with diagnostic delays, greater disability and lower quality of life.[7-10] However, relatively few methods exist to enable the valid and feasible measurement of comorbidities in various settings in MS,[11] despite the need to better understand the impact of comorbidities on MS. This is particularly true at the population level, where methods are needed to assess the impact of MS comorbidities on health services, hospitalizations, physician visits, preventive care and access and other population-level outcomes such as mortality.[12]

Potential data sources to identify the presence of comorbidities at the population level include medical records reviews,

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Author references:

1. Department of Internal Medicine, University of Manitoba, Winnipeg, Manitoba, Canada
2. Department of Community Health Sciences, University of Manitoba, Winnipeg, Manitoba, Canada
3. Department of Medicine, Dalhousie University, Halifax, Nova Scotia, Canada
4. Department of Psychiatry, Dalhousie University, Halifax, Nova Scotia, Canada
5. Capital District Health Authority, Halifax, Canada
6. Department of Medicine (Neurology), University of British Columbia, Vancouver, British Columbia, Canada
7. Department of Epidemiology and Biostatistics and Occupational Health, McGill University, Montréal, Quebec, Canada
8. Research Institute of the McGill University Health Centre, Montréal, Quebec, Canada
9. Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada

CIHR Team in the Epidemiology and Impact of Comorbidity on Multiple Sclerosis includes Ruth Ann Marrie (University of Manitoba, Winnipeg, Manitoba), Bo Nancy Yu (University of Manitoba, Winnipeg, Manitoba), Stella Leung (University of Manitoba, Winnipeg, Manitoba), Lawrence Elliott (University of Manitoba, Winnipeg, Manitoba), Patricia Caetano (University of Manitoba, Winnipeg, Manitoba), James F. Blanchard (University of Manitoba, Winnipeg, Manitoba), Lawrence W. Svenson (University of Alberta, Edmonton, Alberta), Joanne Profetto-McGrath (University of Alberta, Edmonton, Alberta), Sharon Warren (University of Alberta, Edmonton, Alberta), Christina Wolfson (McGill University, Montréal, Quebec), Nathalie Jette (University of Calgary, Calgary, Alberta), Scott B. Patten (University of Calgary, Calgary, Alberta), Charity Evans (University of Saskatchewan, Saskatoon, Saskatchewan), Helen Tremlett (University of British Columbia, Vancouver, British Columbia), John Fisk (Dalhousie University, Halifax, Nova Scotia), Virender Bhan (Dalhousie University, Halifax, Nova Scotia) and Michelle Ploughman (Memorial University, St. John's, Newfoundland).

Correspondence: Ruth Ann Marrie, Departments of Internal Medicine and Community Health Sciences, University of Manitoba, GF-533 Health Sciences Centre, 820 Sherbrook Street, Winnipeg, MB R3A 1R9; Tel.: 204-787-4951; Fax: 204-787-1486; Email: rmarrie@hsc.mb.ca

surveys (interviews or self-report) and administrative (health claims) data.[13] No single source is ideal for every study design—or even for every comorbidity.[14] In some countries, including Canada, administrative data offer an attractive opportunity for cost-effective, population-based comorbidity research[15] and have a track record of successful use for national surveillance of chronic diseases such as diabetes.[16] Administrative case definitions for several physical and mental comorbidities among people with MS have been validated in one Canadian province, Manitoba.[17-20] However, the characteristics of physician claims databases and billing practices vary across jurisdictions:[21] the number of diagnosis fields permitted in physician claims varies, as does the specificity of diagnosis codes based on the number of digits coded, both of which may affect the sensitivity and specificity of case definitions. Thus, the need to assess the performance of such methods in other jurisdictions remains and is particularly important if findings using these methods are to be compared across jurisdictions.

In this study, we compared the performance characteristics of previously developed administrative case definitions for comorbidity in the MS population of 2 Canadian provinces, Manitoba and Nova Scotia, with the goal of establishing methods that could be used to study comorbidity in the MS population across Canada.

Methods

This validation study involved the secondary analysis of linked clinical and administrative data in 2 provinces, Manitoba and Nova Scotia. We present the methods for the work in Manitoba followed by the methods for the work in Nova Scotia.

Manitoba

Setting

The province of Manitoba has a stable population of nearly 1.2 million.[22] The data sources used included provincial health claims data for the period 2001 to 2006 and self-report data from 604 patients with MS covering their lifetime through 2006. The University of Manitoba's Research Ethics Board gave ethical approval for this portion of the study. The Manitoba Health Information Privacy Committee approved administrative data access.

Administrative data

Manitoba Health is the provincial government department responsible for health care delivery to 98% of the Manitoba population.[22] Manitoba Health maintains computerized records of all submitted health services claims, including hospital and physician claims. These claims include a unique personal health identification number (PHIN) for the resident who received the service. The population registry captures sex, dates of birth and death, and dates of provincial health insurance coverage. Hospital discharge abstracts include the unique PHIN, dates of admission and discharge, and up to 16 diagnostic codes. Before 2004 these diagnoses were recorded using 5-digit International Classification of Disease (ICD)-9 codes, and since 2004 the diagnoses have been recorded using ICD-10-CA codes. We used all the diagnoses reported in the discharge abstract database. Each physician claim includes the unique PHIN and 3-digit ICD-9 code for one physician-assigned diagnosis. To protect confidentiality, the linkage in this study (see below) was performed via scrambled PHIN, using anonymized versions of the administrative databases provided by Manitoba Health.

Administrative case definitions of comorbidity

The case definitions used in this study were previously developed and validated in Manitoba using a cohort of people with MS (see Table 1).[17-19,23] Briefly, we generated lists of ICD-9/10 codes that matched the clinical terms for the comorbidities of interest, with these comorbidities chosen based on their perceived importance for MS care. Specifically, these comorbidities were either reported to affect more than 5% of MS patients or the literature suggested an association with clinical outcomes.[7-10,24] We developed several case definitions for each condition, varying the number of hospital and physician claims required and the number of years of data used to classify a person as being affected.[25]

TABLE 1
Administrative (health claims) case definitions used for identifying comorbidity in people with multiple sclerosis in Nova Scotia and Manitoba, Canada

Comorbidity	ICD-9 codes	ICD-10 codes	Number of years of data	Number and type of hospital or physician claims[a]
Hypertension	401–405	I10–I13, I15	2	≥ 1H or ≥ 2P
Hyperlipidemia	272	E780, E782, E784, E785	5	≥ 1H or ≥ 2P
Diabetes	250	E10–E14	5	≥ 1H or ≥ 2P
Heart Disease	410–414	I20–I25	5	≥ 1H or ≥ 2P
Inflammatory bowel disease	555, 556	K50, K51		≥ 5 H or P or, if resident in province < 2 years: ≥ 3 H or P
Epilepsy	345	G40, G41	3	≥ 1H or ≥ 2P
Depression	296.2, 296.3, 298.0, 300.4, 311	F32–F34	2	≥ 1H or ≥ 4P
Anxiety	300.0, 300.2	F40, F41	2	≥ 1H or ≥ 3P

Abbreviations: ICD, International classification of diseases; H, hospital claims; P, physician claims.

[a] For physician claims, the ICD-9 codes were truncated after the 3rd digit.

Manitoba validation cohort

We compared classification of comorbidity according to the administrative case definitions to comorbidity diagnoses based on a reference standard in 604 people with demyelinating disease, aiming to optimize agreement as measured by the kappa statistic (κ) between the 2 data sources. These 604 people were drawn from 2 studies;[26,27] they self-reported their comorbidities using a questionnaire,[27] agreed to medical records review and consented to linkage of their administrative and clinical data. In each of the 2 studies, a trained abstractor blinded to the administrative data used the same standardized data collection form to abstract comorbidity data from the medical record. Participants in one study were asked about a longer list of comorbidities than in the other study, but the formatting of the questions was consistent across both studies. Findings on the validity of these administrative case definitions compared to medical records review have been published elsewhere.[17-20]

For this study, we selected for further evaluation case definitions with reasonable performance characteristics[17-19,23,28] based on sensitivity, specificity and kappa when compared to medical records. Table 1 shows the ICD-9/10 codes and the combination of hospital and physician claims and number of years of data required to meet the various case definitions. The sensitivity and specificity of self-report and medical records for comorbidity may differ, and using different reference standards may contribute unnecessary heterogeneity when comparing the validity of administrative case definitions across studies.[29] We therefore compared the performance of the administrative case definitions to self-report to facilitate comparisons to Nova Scotia where the reference standard was self-report.

People meeting the case definitions were considered affected from the date of the first relevant health claim for these conditions.

Nova Scotia

Setting

The eastern province of Nova Scotia has a population of approximately 945 000.[30] The data sources for the study included provincial health claims (administrative) data for Nova Scotia held by the Population Health Research Unit at Dalhousie University for the 20-year period from 1990 to 2010, and self-report data from patients attending the Dalhousie Multiple Sclerosis Research Unit (DMSRU). Nova Scotia's Capital Health Research Ethics Board gave ethical approval for this portion of the study.

Administrative data

Nova Scotia's provincial health insurance program provides publicly funded care to all residents and maintains computerized records of all submitted health service claims including hospital, physician and prescription claims. Each resident has a unique health care identification number attached to each health service claim. The Insured Patient Registry captures the sex, dates of birth and dates of death for each beneficiary of health services as well as the dates of provincial health insurance coverage.

Hospital discharge abstracts include the patient's health care identification number and diagnostic codes reported using 5-digit ICD-9 codes (up to 2001) or ICD-10-CA codes (as of 2001). We used all available diagnoses reported in the discharge abstract database. From 1989 through 1991 up to 5 diagnoses could be reported, from 1992 through 1995 up to 7 could be reported and from 1996 up to 16 could be reported.

Physician claims include the patient's health care identification number, date of service and an ICD-9 code for the diagnosis. Before 1997 the ICD-9 codes used only 3 digits; after 1997 up to 5 digits could be submitted although 3-digit codes are most commonly used.[21] We used 3-digit ICD-9 codes by truncating the last 2 digits (Table 1) for physician claims to ensure (1) comparability with the administrative case definitions developed in Manitoba; (2) consistency over time in Nova Scotia; and (3) generalizability to other jurisdictions, including Saskatchewan, Ontario, Prince Edward Island and Newfoundland and Labrador, that also use 3-digit codes.[21] This approach is also consistent with that used by the Canadian Chronic Disease Surveillance System (CCDSS, formerly known as the National Diabetes Surveillance System). The CCDSS has developed case definitions for chronic diseases such as diabetes that rely on the "lowest common denominator" to ensure case definitions can be applied in all jurisdictions.[16] Between 1989 and 1996, Nova Scotia physicians submitted only one diagnosis per claim, but as of 1997 they could submit up to 3. Again, to ensure comparability and generalizability of these definitions across Canada and over time, we used only the primary (first) diagnosis submitted for each physician claim in our primary analysis. As a sensitivity analysis, we also evaluated the impact of using all 3 diagnoses submitted on the physician claims expecting that this would improve the sensitivity of administrative data.

Nova Scotia study population

We had previously developed and tested several administrative case definitions for MS, comparing these to medical records including clinic letters, MRI reports, cerebrospinal fluid results and evoked potentials reports.[26] We subsequently evaluated the performance of these case definitions in Nova Scotia.[31] Based on this work, we applied a case definition of 3 or more hospital (any diagnosis field) or physician claims (the primary diagnosis only) for MS. To this population we applied the case definitions for comorbidity developed in Manitoba, the sole exception being the definition for inflammatory bowel disease. Since small numbers of reported cases had precluded validation of this case definition in the MS population in Manitoba, we instead used a case definition that has been validated in the general populations of Manitoba and Quebec.[32,33]

Dalhousie Multiple Sclerosis Research Unit clinical database

The DMSRU, located within a tertiary care hospital, is the only provider of MS specialty care in Nova Scotia. The DMSRU has systematically documented each patient visit since 1980. Since 1998, all Nova Scotia residents who wish to receive provincial funding for MS-specific (disease-modifying) therapies must be evaluated at the DMSRU annually.[34] Patients attending the DMSRU consent to their clinical data being linked to administrative data for research purposes. As of

December 31, 2010, the DMSRU database had captured data on 4409 people evaluated or treated for MS. Mean (standard deviation [SD]) clinical follow-up was 5.37 (6.46) years. Of these, 2751 had definite MS and a mean (SD) duration of clinical follow-up of 7.78 (6.64) years.

Nova Scotia validation cohort

As of September 2006, the DMSRU began capturing comorbidities at the first clinic visit and annually thereafter using a standardized patient self-reported questionnaire; a comorbidity was considered as present if it was ever reported. Patients were asked to report all comorbidities regardless of the date of diagnosis so that conditions that were not actively symptomatic, such as migraines in remission, would still be captured. As of 31 December, 2010, this cohort included 1923 people with definite MS who had a mean (SD) duration of clinical follow-up of 8.83 (6.60) years, and mean (SD) age of MS symptom onset of 33.2 (9.9) years (Table 2). Using their unique health care identification numbers, we linked the validation cohort with administrative data for Nova Scotia MS study population from 1 January, 1990 through 31 December, 2010, with January 1990 representing the earliest date for which we were granted administrative data access.

Statistical analyses

First, we compared the classification of comorbidity according to the administrative case definitions and diagnoses from the validation cohorts by computing, for each comorbidity, sensitivity and specificity of the administrative case definitions compared to self-report data with exact 95% confidence intervals based on the binomial distribution. Given that neither administrative data nor self-report can be considered the ideal or preferred source of comorbidity data,[14,35] we also estimated the agreement between the data sources using kappa statistics (κ) where neither data source was considered the reference standard. Kappa indicates the proportion of agreement beyond chance and is calculated as (observed agreement − chance agreement) ÷ (1 − chance agreement). We interpreted the estimated κ as follows: slight (0 to 0.20), fair (0.21 to 0.40), moderate (0.41 to 0.60), substantial (0.61 to 0.80) and almost perfect agreement (0.81 to 1.0).[36] With the smallest validation cohort sizes of 606 at the study outset, we expected that this would be an adequate sample to detect a $\kappa \geq 0.60$ if the comorbidity affected 3% or more of the cohort and the null hypothesis was $\kappa \geq 0.40$ (lowest acceptable κ), $\alpha = 0.05$ and $\beta = 0.20$.

Statistical analyses used SAS version 9.1 (SAS Institute Inc., Cary, NC, US).

Results

Table 2 shows the characteristics of the validation cohorts from Manitoba and Nova Scotia. Age and sex distributions for both cohorts were consistent with those expected for an MS population.[26] The self-reported frequency of depression, anxiety, diabetes and heart disease were similar in both validation cohorts; however, hypertension and hyperlipidemia were less frequent in Manitoba than in Nova Scotia. In both provinces, the frequency of individual comorbidities was generally similar for administrative data and self-report (Table 2).

In Manitoba, the specificities of the administrative case definitions were over 93% for all conditions compared to self-report (Table 3). The findings were similar in Nova Scotia, with the specificities for all

TABLE 2

Characteristics of the validation cohorts used to identify comorbidities in people with multiple sclerosis in Nova Scotia and Manitoba, Canada

Characteristics	Manitoba validation cohort		Nova Scotia validation cohort	
Count (N)	606		1923	
Period covered by participant self-report	Lifetime to 2006		Lifetime to start of data collection in September 2006–December 2010	
Time period for administrative data (hospital and physician claims)	1984-04-01 to 2007-03-31		1990-01-01 to 2010-12-31	
Female, n (%)	511 (84.4)		1480 (77.0)	
Age at first demyelinating disease claim, mean years (SD)	46.7 (12.3)		43.8 (11.2)	
Comorbidity data source	Self-report	Administrative	Self-report	Administrative
Hypertension (%)	91/576 (15.8)	89/576 (15.4)	466 (24.2)	500 (26.0)
Hyperlipidemia (%)	10/169 (5.9)	12/169 (7.1)	329 (17.1)	257 (13.3)
Diabetes (%)	30/606 (4.9)	29/606 (4.8)	127 (6.6)	151 (7.8)
Heart Disease (%)	16/598 (2.5)	26/598 (4.4)	65 (3.4)	105 (5.5)
Inflammatory bowel disease (%)	–	–	32 (1.7)	21 (1.1)
Epilepsy (%)	–	–	55 (2.9)	51 (2.7)
Depression (%)	31/128 (24.2)	23/128 (18.0)	562 (29.2)	522 (27.1)
Anxiety (%)	58/405 (14.3)	41/405 (10.1)	339 (17.6)	614 (31.9)

Abbreviation: SD, standard deviation.

– : Data not available.

TABLE 3
Performance of administrative claims comorbidity definitions compared to self-report for people with multiple sclerosis in Nova Scotia and Manitoba, Canada

Comorbidity	Province (Number of diagnosis fields)	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)	Kappa (95% CI)
Hypertension	Manitoba (1)	0.80 (0.71–0.88)	0.96 (0.94–0.98)	0.79 (0.69–0.87)	0.96 (0.94–0.98)	0.76 (0.69–0.84)
	Nova Scotia (1)	0.79 (0.75–0.83)	0.91 (0.89–0.92)	0.74 (0.70–0.77)	0.93 (0.92–0.94)	0.68 (0.64–0.72)
	Nova Scotia (3)	0.79 (0.75–0.83)	0.90 (0.89–0.92)	0.73 (0.68–0.76)	0.93 (0.92–0.94)	0.68 (0.64–0.71)
Hyperlipidemia	Manitoba (1)	0.50 (0.21–0.97)	0.97 (0.94–0.99)	0.60 (0.26–0.88)	0.96 (0.92–0.99)	0.51 (0.25–0.78)
	Nova Scotia (1)	0.53 (0.48–0.59)	0.95 (0.94–0.96)	0.68 (0.62–0.74)	0.91 (0.89–0.92)	0.53 (0.47–0.58)
	Nova Scotia (3)	0.56 (0.50–0.61)	0.94 (0.93–0.95)	0.67 (0.61–0.73)	0.91 (0.90–0.93)	0.54 (0.49–0.59)
Diabetes	Manitoba (1)	0.67 (0.47–0.83)	0.98 (0.97–0.99)	0.60 (0.36–0.81)	0.99 (0.98–0.99)	0.66 (0.52–0.80)
	Nova Scotia (1)	0.80 (0.71–0.86)	0.97 (0.96–0.98)	0.67 (0.59–0.74)	0.99 (0.98–0.99)	0.70 (0.64–0.77)
	Nova Scotia (3)	0.80 (0.71–0.86)	0.97 (0.96–0.98)	0.67 (0.58–0.74)	0.99 (0.98–0.99)	0.70 (0.64–0.77)
Heart disease	Manitoba (1)	0.42 (0.23–0.63)	0.99 (0.98–0.99)	0.69 (0.41–0.89)	0.97 (0.96–0.98)	0.51 (0.32–0.69)
	Nova Scotia (1)	0.58 (0.46–0.71)	0.96 (0.95–0.97)	0.36 (0.27–0.46)	0.99 (0.98–0.99)	0.42 (0.33–0.52)
	Nova Scotia (3)	0.58 (0.46–0.71)	0.96 (0.95–0.97)	0.36 (0.27–0.46)	0.99 (0.98–0.99)	0.42 (0.33–0.52)
Inflammatory bowel disease[a]	Nova Scotia (1)	0.59 (0.41–0.76)	1.0 (1.0–1.0)	0.90 (0.70–0.99)	0.99 (0.99–1.0)	0.71 (0.57–0.85)
	Nova Scotia (3)	0.59 (0.41–0.76)	1.0 (1.0–1.0)	0.90 (0.70–0.99)	0.99 (0.99–1.0)	0.71 (0.57–0.85)
Epilepsy[a]	Nova Scotia (1)	0.47 (0.34–0.61)	0.99 (0.98–0.99)	0.51 (0.37–0.65)	0.98 (0.98–0.99)	0.48 (0.36–0.60)
	Nova Scotia (3)	0.47 (0.34–0.61)	0.99 (0.98–0.99)	0.51 (0.37–0.65)	0.98 (0.98–0.99)	0.48 (0.36–0.60)
Depression	Manitoba (1)	0.55 (0.36–0.73)	0.94 (0.87–0.98)	0.74 (0.52–0.90)	0.87 (0.79–0.92)	0.53 (0.36–0.71)
	Nova Scotia (1)	0.49 (0.45–0.54)	0.82 (0.80–0.84)	0.53 (0.48–0.57)	0.80 (0.77–0.82)	0.32 (0.27–0.36)
	Nova Scotia (3)	0.49 (0.45–0.54)	0.82 (0.80–0.84)	0.53 (0.48–0.57)	0.80 (0.77–0.82)	0.32 (0.27–0.36)
Anxiety	Manitoba (1)	0.29 (0.18–0.43)	0.93 (0.90–0.95)	0.41 (0.26–0.58)	0.89 (0.85–0.92)	0.26 (0.13–0.38)
	Nova Scotia (1)	0.62 (0.56–0.67)	0.74 (0.72–0.77)	0.34 (0.30–0.38)	0.90 (0.88–0.92)	0.27 (0.23–0.32)
	Nova Scotia (3)	0.62 (0.57–0.67)	0.74 (0.72–0.76)	0.34 (0.30–0.38)	0.90 (0.88–0.92)	0.27 (0.23–0.32)

Abbreviations: CI, confidence interval; NPV, negative predictive value; PPV, positive predictive value.

[a] Insufficient number of cases reported in Manitoba (< 5).

case definitions exceeding 91%, except for depression (82%) and anxiety (74%). In both provinces, the sensitivities of the administrative case definitions were more variable than the specificities. The sensitivity was particularly low for anxiety, being as low as 29% in Manitoba.

In Manitoba, agreement between the administrative case definitions and self-report was substantial for hypertension and diabetes; moderate for hyperlipidemia, heart disease and depression; and fair for anxiety. Agreement was slightly lower in Nova Scotia for hypertension and hyperlipidemia but the same for diabetes and heart disease. Agreement was lower in Nova Scotia and more discrepant for depression. The specificity of the case definition for anxiety was lower in Nova Scotia than in Manitoba. Two conditions were tested solely in Nova Scotia; agreement was substantial for inflammatory bowel disease and moderate for epilepsy.

As a sensitivity analysis, we also evaluated the impact of using all 3 diagnoses submitted on the physician claims rather than the first diagnosis, but this had no meaningful impact on the performance of our case definitions (see Table 3).

Discussion

We tested the performance of administrative case definitions for common comorbidities in MS populations from 2 Canadian provinces, Nova Scotia and Manitoba. The prevalence of these comorbidities differed somewhat across populations, consistent with variation seen in other studies.[11] Our study demonstrates a good overall performance for several important comorbidity definitions using health administrative data in the MS populations in these 2 provinces. This represents a major step forward in developing a pan-Canadian monitoring system for comorbidity in MS, an increasingly important issue for the population, health system and policy makers.

However, our study also highlights the importance of developing a robust methodology and fully understanding the strengths and limitations of the available data sources before moving forward with such a system. For instance, agreement between administrative case definitions differed by comorbidity.

Our findings also highlight the general importance of testing the performance of case definitions developed in one jurisdiction or population before applying them elsewhere.

Administrative data are accessible, cost-effective and population-based. However, since these data are collected for health system management they must be validated for use in research. The utility of these data may vary across populations and conditions[25,29] and validity may appear to vary depending on study design.[29] While the sensitivity of our administrative case definitions varied, specificity was high, typically exceeding 90% for physical comorbidities, consistent with our previous observations in Manitoba.[17-19,23] The consistency of the performance of the case definitions in MS populations in Manitoba and Nova Scotia supports their use in other Canadian provinces. While the specificities of physical comorbidities were high, those for the mental comorbidities were somewhat lower, ranging from 74% to 94%. Other validation studies of administrative case definitions in Canada also noted difficulties in distinguishing depression from anxiety when using 3-digit ICD codes due to the lack of specificity at this level.[37,38] For example, the same code (300) describes dysthymic disorder (300.4), a form of chronic depression, and anxiety states (300.0). Similarly, the code 296 describes major depressive disorder single episode (296.2) and bipolar disorder single manic episode (296.0). In addition to difficulties distinguishing depression and anxiety, other efforts to validate case definitions for depression have reported poor concordance with depression as measured using the Composite International Diagnostic Interview.[38] One study among people treated with antidepressants in Saskatchewan, Canada found that agreement between depression identified using physician claims and in medical records was moderate (κ = 0.54), better than we observed.[39] In Manitoba, where population-based prescription claims data are available, we had found that the best-performing administrative case definitions for psychiatric comorbidities, including depression and anxiety, used prescription claims.[18] However, Nova Scotia has no population-based prescription database. This is also the case in several other Canadian jurisdictions, thereby limiting the use of prescription claims–based definitions at the national level. Agreement between the case definitions and self-report for depression was also lower in Nova Scotia than that in Manitoba. This suggests that additional caution is required in using case definitions for psychiatric comorbidity.

Several of the case definitions we used had been originally developed for use in the general population but were considered to perform adequately in the MS population compared to other potential case definitions tested in Manitoba.[17,19,28] These included the case definitions for hypertension, heart disease and inflammatory bowel disease. We used the CCDSS definition of hypertension; this definition performed similarly in the 2 MS populations studied. We found a sensitivity of 79% to 80%, specificity of 91% to 96% and κ of 0.68 to 0.76. Studies in the general population from Ontario and Manitoba that tested these case definitions found similar sensitivities of 69% to 73%, specificities of 95% and κ of 0.67 to 0.70.[25,40] The case definition for heart disease showed moderate agreement with self-report in Manitoba (κ = 0.51) and Nova Scotia (κ = 0.42), consistent with findings in the Manitoba general population (κ = 0.55).[25] For inflammatory bowel disease we applied a case definition developed in the Manitoba general population to the Nova Scotia MS population and found a sensitivity of 59%, specificity of 100% and κ of 0.71. The specificity and agreement compares favourably to the initial findings in Manitoba where the specificity of using self-report was 91% and κ was 0.79 to 0.80. The sensitivity, however, was lower than that reported for the general population in either Manitoba (> 87%) or Quebec (97%). The lower sensitivity of general population case definitions when applied to the MS population is also evident for diabetes and epilepsy. We had previously evaluated the performance of the CCDSS definition of diabetes in the Manitoba MS population and found a sensitivity of only 50%, substantially lower than the 79.5% to 86% reported in the general population.[25,41] We found that modifying the CCDSS definition to use 5 years of data rather than 2 improved sensitivity;[17] this modified case definition had an 80% sensitivity in the Nova Scotia population while retaining a high specificity of 97%. For epilepsy, we found a sensitivity of 47% and specificity of 99% as compared to self-report. The definition that we used for epilepsy—1 hospitalization or 2 physician claims in 3 years—has not been tested in the general population in Canada. However, in the Alberta general population a case definition of 1 hospitalization or 2 physician claims in 2 years had a substantially higher sensitivity of 88.9% with a similar specificity of 92.4%.[42] Overall, these findings suggest that case definitions developed in the general population may not perform as well when applied to specific chronic disease populations and that their validity should be assessed before they are used.

The lower sensitivity of case definitions for comorbidity in the MS population than that reported for the general population may reflect the known limitations of administrative data: comorbidity may be under-reported in hospital claims due to coding biases.[43] Sensitivity of case definitions may also be influenced by the number of diagnoses coded, particularly in physician claims as much of the care for chronic disease is delivered in the outpatient setting. The number of diagnosis fields recorded on physician claims varies, being limited to only 1 in most provinces but up to 3 in British Columbia, 3 in Alberta, 3 in Nova Scotia since 1997, 2 in the Yukon before 2006 and unlimited thereafter and 11 in Nunavut.[21] Such differences in coding could lead to apparent differences in disease prevalence across provinces. For this reason we evaluated the impact of using 3 diagnoses rather than just 1. Although we did not find any major influence of the number of diagnosis fields used on the sensitivity or specificity of our case definitions, these findings should be verified in those jurisdictions where 3 diagnosis fields are available.

We did not attempt to evaluate the impact of the changes in fee-for-service billing as physicians switch to alternative payment plans but that factor may also vary across provinces[21] and influence the sensitivity of administrative data.

We used self-report data as our reference standard, recognizing that no data source can be considered a true gold standard for comorbidity and that some of the discordance between the self-report and administrative data that we observed may be due to limitations in both data sources. Gathering robust self-report data poses its own challenges as respondents may fail to recall all medical conditions with which they have been diagnosed, may fail to report some conditions due to social desirability bias or may misunderstand diagnoses reported to them. Nonetheless, obtaining these data is often easier and more cost effective than gaining access to comprehensive medical records information. Review of the records of a single provider has been found to have lower sensitivity for chronic disease than review of the records of all providers visited by a person,[44] yet it can be difficult to obtain access to all such records due to cost, privacy and other practical considerations. A comorbidity index based on administrative data outperformed a comorbidity index based on data from a single day review of hospital charts.[45] While the validity of self-report has been shown to vary by condition, such data appear to be reasonably accurate for well defined, chronic disorders that require ongoing care or that cause disability, such as those we investigated in our study.[14] Further, self-report may predict health-related quality of life and functional status more accurately than medical records data.[46] Together such findings suggest that, for at least some chronic conditions, self-report data are an adequate comparator for the validation of administrative case definitions.

Strengths of our study include the large cohorts involved and the availability of comparative data from Manitoba and Nova Scotia. Our findings that the performance characteristics of administrative case definitions for several comorbidities commonly observed in MS are relatively stable across jurisdictions suggests that they can be used effectively for population-based studies investigating the epidemiology and impact of comorbidity in MS. Case definitions for psychiatric comorbidities require further optimization, and further work is needed to develop methods to assess other comorbidities of potential relevance to people with MS.

Conflicts of interest and acknowledgements

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Building knowledge development and exchange capacity in Canada: lessons from Youth Excel

B. Riley, PhD; K. Wong, MSc; S. Manske, EdD

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Abstract

Introduction: Youth Excel was a 3-year pan-Canadian initiative to advance youth health through improving knowledge development and exchange (KDE) capacity. KDE capacity refers to an improvement cycle linking evidence and action. Capacities include local surveillance of youth behaviours; knowledge exchange; skills, resources and a supportive environment to use knowledge; and evaluation.

Methods: Interviews were conducted with Youth Excel members, including 7 provincial teams and 2 national organizations. Interviews explored participant experiences with building KDE capacity.

Results: Local surveillance systems were considered the backbone to KDE capacity, strengthened by co-ordinating surveys within and across jurisdictions and using common indicators and measures. The most effective knowledge exchange included tailored products and opportunities for dialogue and action planning. Evaluation is the least developed KDE component. Building KDE capacity requires frequent dialogue, mutually beneficial partnerships and trust. It also requires attention to language, vision, strategic leadership and funding.

Conclusions: Youth Excel reinforces the need for a KDE system to improve youth health that will require new perspectives and sustained commitment from individual champions and relevant organizations.

Keywords: knowledge development and exchange, capacity building, youth health, evidence to action, evidence-informed public health, local surveillance

Introduction

The capacity to generate and use relevant and high quality evidence is fundamental to public health. Although described in different ways, core functions of public health include assessment of health patterns and trends as well as developing, implementing and evaluating health programs and services in partnership with relevant collaborators.[1,2] The limited capacity to perform these functions has been well-documented in many jurisdictions, as have calls to strengthen public health capacity.[3-6]

In response to these calls, a pan-Canadian team established Youth Excel, a 3-year initiative funded by the Canadian Partnership Against Cancer's Coalitions Linking Action and Science for Prevention (CLASP).[7] The goal of Youth Excel was to strengthen the capacities for generating and using evidence—referred to as knowledge development and exchange (KDE)—to advance the health of Canadian youth aged 10 to 18 years. KDE involves improving the cycle linking evidence and action, including local surveillance of youth behaviours; fostering the skills and resources and the supportive environment to use and exchange knowledge; and evaluation (described in more detail below).

An internal, mixed methods evaluation of Youth Excel included a qualitative study to determine the lessons learned about building KDE capacity. This paper reports the results of the qualitative study.

Research setting: Youth Excel

Promoting population-level prevention and health with a particular focus on tobacco-free living as well as physical activity and healthy eating is the stated priority of government and non-governmental organizations in Canada,[8] the United States[9] and worldwide.[10] Youth Excel (**Youth** Health Collaborative: '**Excel**erating' EVIDENCE-informed ACTION) addressed these priorities among youth aged 10 through 18 years of age. Like other CLASPs, the aim of Youth Excel was to accelerate the dissemination and implementation of evidence-informed policy and practice through collaborating across jurisdictions and across research, policy and practice sectors. Youth Excel focused on the foundational capacities that enable evidence-informed decisions and actions. As the origins and design of Youth Excel are described in detail elsewhere,[11] only a brief description follows.

Youth Excel was begun by a group of people who had collaborated on other projects and who shared a common goal of ensuring that youth health priorities, programs and policies in Canada are evidence-informed. Teams from 7 provinces (BC, AB, MB, ON, NB, NL, PE) and 2 national organizations—the Pan-Canadian

Author reference:

Propel Centre for Population Health Impact, Faculty of Applied Health Sciences, University of Waterloo, Waterloo, Ontario, Canada

Correspondence: Katy Wong, Senior Manager, Propel Centre for Population Health Impact, Faculty of Applied Health Sciences, University of Waterloo, 200 University Avenue West, Waterloo, ON N2L 3G1; Tel.: 519-888-4567, ext. 36554; Fax: 519-886-6424; Email: kwong@uwaterloo.ca

Joint Consortium for School Health (JCSH) and the Propel Centre for Population Health Impact (Propel)—envisioned a future in which all federal, provincial and territorial jurisdictions in Canada would routinely convene leaders in policy, practice and research to (1) jointly set priorities for action, identifying highest needs and determining what interventions are the most promising; (2) act on priorities; (3) learn from actions and evaluate promising approaches and (4) continuously improve policies and programs that enhance youth health. This vision for Youth Excel represents a quality improvement cycle that links evidence and action. Youth Excel refers to this cycle, which includes local surveillance of youth behaviours, knowledge exchange, the skills and conditions to use the evidence and the evaluation, as KDE capacity (Figure 1).

To strengthen KDE capacity, Youth Excel capitalized on existing partnerships and built new ones. Members worked in research, policy and practice and the health and education sectors, and had up to 16 years of project-specific collaborations before creating Youth Excel. In addition, the stage of development and initiatives related to KDE capacity varied substantially across the 7 participating provincial teams (see Table 1). This variability provided a "natural experiment" that guided the aims and activities of Youth Excel.

Youth Excel members developed 5 main activities to strengthen KDE capacity. The first capitalized on the more advanced KDE developments in some provinces. In-depth, comparative case studies of KDE capacity were conducted in 4 provinces (AB, MB, NB, PE). The second main activity was establishing national forums that convened people from policy, practice and research to learn, share and uncover ways to build KDE capacity. For example, one national forum focused on sharing lessons from the provincial case studies and providing an opportunity for action planning within provinces and territories. The third activity was establishing provincial forums, and during the 3-year period 15 forums that built on the activities and outcomes of the national forums were hosted. Youth Excel's fourth main activity was hosting a peer learning exchange program targeted across provinces, health and education disciplines, and research, policy and practice sectors to strengthen collaboration and learning about KDE capacity across diverse groups. Lastly, Youth Excel collaborated with experts in research, policy and practice from across Canada to develop a core set of indicators and measures for youth tobacco use, physical activity and healthy eating that could be used as part of any surveillance or monitoring tool.

Methods

Telephone interviews were conducted with Youth Excel members from provincial teams (n = 7) and national organizations (n = 2). Participants included 21 Youth Excel researchers (n = 12), practitioners (n = 5) and policy makers (n = 4) across 12 interviews. The unit of data collection and analysis was each national organization and each provincial team. Group interviews allowed for the inclusion of different perspectives from each organization and team. Over one-third (n = 8) of the respondents worked directly at the local or community level. Direct involvement in the design, implementation and/or evaluation of Youth Excel was the main selection criteria for interview participants, since the purpose of the interviews was to understand assets, drivers and constraints for building KDE capacity up to the end of Youth Excel funding in November 2011. Two of the authors (KW, SM) conducted the approximately one-hour long interviews in November and December 2011. A 12-question, semi-structured interview guide developed by Youth Excel's Evaluation Working Group guided the interviews. This interview guide was pre-circulated to allow interview participants to request input from other Youth Excel members in their jurisdiction.

Interviews were audio-recorded, transcribed and imported into NVivo 9 (QSR International, Doncaster, Vic, AU) using 3 coding passes. Each pass was structured around one of the 4 components of KDE capacity in an effort to understand the essential ingredients needed to build each aspect of KDE capacity.

This first pass of the analysis involved coding the text from the interviews, line-by-line, into the specific KDE component categories. This involved segmenting and labelling interview text, assigning this

FIGURE 1
Knowledge development and exchange capacity cycle

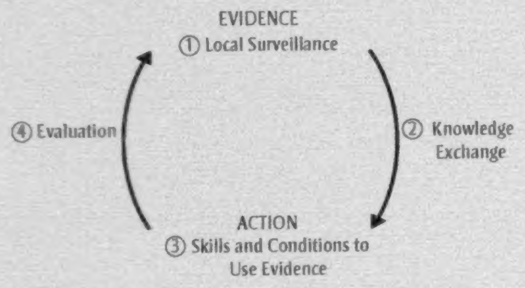

TABLE 1
Provincial and national Youth Excel members and their history of collaboration

Provincial Partners (lead organization)	Description of partner and collaboration history
British Columbia (University of Victoria)	Youth Excel members in BC provide close ties between research and practice. A key player moved from government (health) to academia in 2004 and has maintained strong links through the development and evaluation of government strategies such as *Action Schools! BC*, a provincial initiative facilitating systemic change for healthy weights using comprehensive school health approaches and a Sugar Sweetened Beverage Education Program. Key players in BC and AB collaborate to ensure their provinces gather comparable data. Provincial leads in BC and ON collaborate on research to inform dissemination decisions.
Alberta (University of Alberta)	The University of Alberta's Population Health Intervention Research Unit (PHIRU) conducts population intervention studies in AB, PE and NS. For example, PHIRU evaluates Alberta Health and Wellness's investment in healthy eating and active living with the REAL Kids survey of grade 5 students. Another collaborative project, APPLE Schools, evaluates the comprehensive school health model. EverActive Schools, a comprehensive school health initiative, also partners with Youth Excel. PHIRU and EverActive Schools also partner with government to assess other models for implementing comprehensive school health initiatives.
Manitoba (CancerCare Manitoba)	MB's Partners in Planning for Healthy Living (PPHL) conducts local risk factor surveillance and knowledge development and exchange for local planning with youth health as an initial focus. Founded in 2006, PPHL includes (1) all 11 MB Regional Health Authorities; (2) non-governmental organizations (Alliance for the Prevention of Chronic Disease, Canadian Cancer Society–MB Division, CancerCare Manitoba, Heart and Stroke Foundation of MB); (3) 3 government ministries (Health and Healthy Living; Education Citizenship and Youth; Healthy Child MB Office); (4) Health in Common and (5) the regional Public Health Agency of Canada (MB/SK Region). PPHL aligns mandates, priorities, investments and activities across organizations to share resources and collaborate in supporting the use of evidence to plan interventions that promote healthy living in communities across MB. MB has completed the Youth Health Survey, which facilitates activity based on local data collection.
Ontario (Public Health Ontario)	Ontario collaborators have established numerous interconnections. They have conducted a wide range of projects, including SHAPES (see Propel description below). This provincial collaboration includes research leaders from Propel and the Ontario Ministry of Health and Long-Term Care (formerly Ministry of Health Promotion), regional public health departments and Public Health Ontario (PHO). PHO provides scientific and technical advice for those working to protect and promote the health of Ontarians. PHO builds KDE capacity via Ontario's Health Promotion Resource Centres, conducts mission-related research and evaluation and contributes evidence directly to policy and practice.
New Brunswick (University of New Brunswick)	The NB Department of Wellness, Culture & Sport, Department of Education and University of New Brunswick's Health & Education Research Group (HERG) teamed up to work on NB's Youth Wellness strategy. Key players have worked together on tobacco control for 10 years and led the NB Anti-Tobacco Coalition (including provincial youth forums). NB partners assessed and promoted youth health in all provincial schools in 3-year cycles starting 2006/07, with follow-up support to school communities to identify priorities, community strengths and paths for action.
Newfoundland and Labrador (Memorial University)	Through the Healthy Schools Healthy Students Initiative (HSHS), the Government of Newfoundland and Labrador supports a Comprehensive School Health approach with a cross-department (Health, Education, Recreation, Environmental Health) and a provincial HSHS committee. The provincial HSHS committee involves researchers, school health co-ordinators, policy makers and officials from the school districts and health authorities. HSHS has supported various policies and projects: implementation of district smoke-free school policies, development of School Food Guidelines, development, implementation and evaluation of Active Schools Projects in all school districts and implementation of the new physical education curriculum.
Prince Edward Island (University of Prince Edward Island)	Since 2005, University of Prince Edward Island's (UPEI) School Health Research (CSHR) Group has worked with the PE Department of Education and Early Childhood Development to improve youth health. PE Education has funded 3 cycles of CSHR student data collection data in a census of PE schools using the SHAPES system (see Propel below for a description). As the focus shifts from data collection to knowledge exchange, PE partners have linked with other longstanding partners (up to 2 decades) including Canadian Cancer Society – PE Division, the PE Department of Health, the province's 3 school boards and PE schools. These groups also have connections to provincial alliances relevant to Youth Excel including the PE Tobacco Reduction Alliance, Recreation PE and the Healthy Eating Alliance.
National Partners	
Pan-Canadian Joint Consortium for School Health (JCSH)	JCSH emerged from a 2005 agreement among the provincial and territorial ministers of Health and Education and the Public Health Agency of Canada to provide leadership and build the capacity of the education and health sectors to work together to improve student health and achievement. JCSH has led an unprecedented government effort to promote collaboration within and across jurisdictions. It has undertaken a number of activities that form the basis for KDE capacity. JCSH convened data monitoring meetings with invited experts and policy makers from across Canada to advance the issues of data collection and surveillance as they relate to the overall school health agenda. With Propel it developed and tested the Healthy School Planner, an assessment tool based on the Comprehensive School Health framework, to gather evidence that guides planning and action by schools and their partners. JCSH has also proactively connected with key national organizations such as the Public Health Network and the Canadian Association of Principals to facilitate moving the agenda to ensure connection and alignment.
Propel Centre for Population Health Impact (Propel)	Propel, a collaborative enterprise, conducts research, evaluation and knowledge exchange to accelerate improvements in the health of populations. Focus areas include tobacco control, youth health, chronic disease prevention and capacity development. Propel's niche is linking evidence and action to prevent cancer and other chronic diseases. Propel works with over 200 leaders in science, policy and practice from across Canada to jointly plan, conduct and act on studies that lead to improvements in policies and programs and guide change. In addition to developing the Healthy School Planner with JCSH, Propel developed the School Health Action Planning and Evaluation System (SHAPES), an efficient means to gather student-level evidence on key health topics and feed that information back to schools and their partners. Propel is committed to moving evidence into action, in part by serving a convening role.

Abbreviations: AB, Alberta; BC, British Columbia; KDE, knowledge development and exchange; MB, Manitoba; NB, New Brunswick; NS, Nova Scotia; ON, Ontario; PE, Prince Edward Island; SK, Saskatchewan.

coded text to appropriate KDE component categories and then reassigning to other categories as appropriate. After all the interviews had been coded in this way, the codes were reviewed to ensure they fit into that KDE capacity component. The second pass sorted the distilled codes into categories within each KDE component.

The third coding pass identified themes specific to each KDE capacity component. Criteria for identifying themes were based on (1) whether the majority of participants discussed the theme in relation to that KDE component and/or (2) the extent to which participants discussed that theme within or across interviews. In addition, interviews that indicated the presence of a theme (e.g. mutually beneficial partnerships, building trust, frequent dialogue, etc.) specific to a KDE component were continually compared with those that did not have that theme to discern whether, in fact, the theme was an essential ingredient. Finally, themes were compared and contrasted across the 4 KDE components to identify those that were cross-cutting.

All research methods were reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. All the participants gave informed consent.

We enhanced confidence in our findings in several ways. The study included the lead investigator and staff from each provincial team and national organization who were most actively involved in Youth Excel. The small-group unstructured interviews (2–3 people) efficiently captured the breadth and depth of experience in each jurisdiction. To avoid introducing bias in responses, the purpose of the interviews and their timing did not conflict with any funding applications either in preparation or under review. A draft manuscript was circulated to all participants, who indicated the results resonated with their experience. Finally, an individual unaffiliated with Youth Excel conducted the analyses.

The study was purposely limited to members of Youth Excel so as to explore KDE capacity; the research perspective rather than a policy and practice perspective was more dominant among those interviewed, consistent with affiliations of Youth Excel members. Also, the experience of respondents varied across the 4 KDE components; results for the first 2 components are based on direct and in-depth experience, whereas results for the third and fourth components are based on fewer experiences.

Results

Results are organized into each of the 4 KDE capacity components (see Figure 1) and into overall KDE capacity for themes that cut across 2 or more components. Results reflect participants' experiences in building KDE capacity, both before and during the 3-year Youth Excel initiative. Interview quotation perspectives are coded according to sector (R = research; P = policy; Pr = practice) and jurisdiction (Prov = provincial; Nat = national) to retain respondents' anonymity.

Component 1: Local surveillance system

Local surveillance systems collect data on stakeholder-identified priority topics considered foundational to KDE capacity, for example, youth tobacco use, physical activity, healthy eating and positive mental health.

> The biggest difference now is that we have measurable data that we never had before. We had opinions. We had a little bit of national data. We couldn't walk in and have the conversations we are having with government if we didn't have the evidence, so having these provincial data for our students in our province, it helps me at a school level (R; Prov).

The following themes reflect respondents' insights on elements of a local surveillance system and how to build such systems in different jurisdictions.

Mutually beneficial partnerships

Youth Excel members underscored the importance of relationships and networks in building an effective local surveillance system (e.g. "Knowledge development and exchange is all about building relationships" [R; Prov]). Leveraging existing networks was especially important, as was building partnerships with "connectors"—individuals with links to other researchers, practitioners, policy makers—and with "negotiators"—individuals who know how to seek and involve other stakeholders and who accelerate buy-in and use of complementary strengths.

Youth Excel members considered government to be a key player, though the desired role varied by jurisdiction. Some indicated that a data collection tool with a government logo or endorsement is taken more seriously than one without.

> I know from my experience that if I hand out a survey that has not only a project logo but also the logos of the government of [province] on it ... it has been taken more seriously, and so I was very particular that when I started this contract with the government that I referred to that as a partnership so that I could have their logo on the survey (R; Prov).

Building trust

Establishing and maintaining local surveillance systems required building trust among players. Negotiating various perspectives across research, policy and practice and establishing shared understanding among these diverse players was complex and difficult at times. To build trust, members needed a non-judgmental environment, a willingness and ability to adapt, transparency and an enduring commitment to the vision and values established by the team.

> I think that speaks to our real belief in building trust and relationships to form true partnerships and allowing enough time for that to develop (R; Prov).

Frequent dialogue

Youth Excel members considered regular and tailored face-to-face meetings with a diverse group to be essential. That such meetings included individuals from outside of the health and education sectors who recognized the added value and practical application of a surveillance system was also considered important.

Members reported that frequent meetings facilitate "democratic conversations," both internal and external partner engagement and problem-solving of complex issues such as co-ordinating multiple existing surveys.

Co-ordination of surveys

At national, provincial and local levels, numerous surveys collect data on unique and common topics related to youth health. For best use of resources and to decrease burden on respondents and organizations, Youth Excel members noted the advantages of co-ordinating surveys at all jurisdictional levels:

> …the province as a whole is in discussion around how we can, number 1, take existing surveys and co-ordinate them, and [number] 2, fill in the gaps that aren't currently being covered particularly around childhood obesity, physical activity, healthy eating (R; Prov).

They also noted the need for a deep understanding of diverse contexts and the value of bringing together the right players to accomplish this co-ordination.

Core Indicators and Measures (CIM)

Many respondents expressed the need to use consistent questions across surveillance/monitoring tools over time to facilitate meaningful comparisons between settings and populations. The most valuable features of the Youth Excel–developed CIMs were the consensus process involving research, policy and practice and their flexible use. For example, CIMs for tobacco use, physical activity and healthy eating can be used as separate modules, together and/or integrated with other questions.

> Ideally, I would like to see all 3 put into surveys. It addresses what we're hearing from schools, that they're moving away from single topic interventions. As they're looking at more comprehensive strategies to tackle a number of health issues, we need a tool that can appropriately evaluate them (R; Prov).

More information on CIMs is available elsewhere.[12] Adoption and the subsequent use of CIMs will take more time although doing so is essential to ensuring the usefulness of surveillance to science and practice.

Component 2: Knowledge exchange

Knowledge exchange within Youth Excel included specific products and processes that use surveillance data for planning and action and to facilitate peer learning about building KDE capacities.

Transforming data into knowledge products

Data from surveillance systems needs to be transformed into information to help set clear direction in new policies and programs, evaluate existing policies and initiatives and for strategic planning purposes. The most common transformation mentioned by Youth Excel members was of data in reports. Reports at all levels—provincial-, local- or school-level reports that provide comparative national and/or provincial-level data—are all important to their intended audience. There was particular emphasis on the value of local-level data:

> People in the province realized how valuable their local data are and, in our last provincial round table, people really want that. They don't want to run even a small intervention without having data at their school levels (R; Prov).

The right people

Respondents indicated that knowledge brokers—people who translate, package, interpret and communicate information—serve a valuable function especially during "knowledge exchange periods" that follow data collection periods (e.g. school years).

> We were using natural knowledge brokers that were out there, healthy learners in school programs, public health nurses, community groups, and others who were in a position to bring the data forward alongside of discussions around interventions (R; Prov).

Sharing and learning across sectors and jurisdictions

Respondents emphatically supported systematic ways of learning from each other around a common purpose. They placed a high value on the national- and provincial-level forums that Youth Excel convened. Dialogue with other jurisdictions or provinces was "inspirational" and helped Youth Excel members develop ideas and validate insights.

> The round table also gave us the opportunity to connect with partners such as Aboriginal Affairs and Northern Development Canada, provinces and territories, and others working in the education sector. The round table was valuable as it stimulated thinking and encouraged partners to work together to promote comprehensive school health (P; Nat).

Relationships across the country were easier to sustain with the continuity of interactions at forums:

> Knowing that there is that kind of continuity there—it builds the trust and the foundation and it enables us to pursue those linkages and assist us in our consortium endeavours or those related to [Youth Excel] CLASP on a more regular basis (P; Nat).

At least twice-yearly provincial network meetings allowed partners within each province to develop a shared agenda about KDE for youth health. These formal and informal networks created important opportunities for individuals to provide leadership, strengthen relationships and foster a helpful, non-hierarchical means of working.

> Ideally, we'd have twice-yearly meetings of the provincial network. By the second provincial round table, we could see how much people valued the event. It developed a sort of hype. People were emailing me all the time saying they'd heard of the meeting, and asking to come. The invitation list doubled in size overnight. We got a

> great balance between representatives from health, education, research, policy practice—even tourism, parks and rec, and student leaders (R; Prov).

Linking provincial knowledge exchange forums with a related conference or event (e.g. healthy schools conference) helped recruit players and extend the reach of the KDE agenda.

Webinars
Webinars were a productive medium for KDE and, compared with traditional meetings, presented fewer barriers to attendance. Aside from doing away with cost and travel time, webinars could be recorded and made available for subsequent access, expanding their reach even further.

> [Webinars are] a vehicle for people to get to know and look for current information about what is really going on. It's a process for people to get together and discuss and create interest and willingness to work together (R; Prov).

Component 3: Skills and conditions for using evidence

Consistent with the previous 2 components, respondents considered partnerships the most essential driver for developing the skills and conditions to use evidence. Researchers need practitioners and policy makers who value and request data to help inform intervention implementation and policy decisions. In turn, practice and policy makers need researchers to produce the relevant evidence to inform the right decisions. Researchers who can "pull up data instantly" are especially valuable as are knowledge brokers who know what data exist and can examine and understand the data and take appropriate action. Although "previously, the sectors had been working in relative isolation... there's a new ethos that says we need all sectors coming together to act on our agendas" (R; Prov).

Respondents noted the importance of a supportive environment for putting information to use, training opportunities for people to do knowledge exchange in schools and initiatives that require the use of knowledge products (e.g. school grant programs based on school-level data).

Component 4: Evaluation

Respondents acknowledged the need to evaluate—to "learn as we go"—and that the capacity to generate evidence from action is the most under-developed of the 4 KDE capacity components. The capacity to produce the most useful information hinges on appropriate evaluations being in place. A shared ideal view was that evaluations need to be embedded into the system, make optimal use of the local surveillance system and ensure timely release of findings. Evaluations would also capture a wide range of evidence, including the experience of working with innovative interventions, lessons learned and better practices among local researchers or practitioners as well as those in other jurisdictions.

Overall KDE capacity

Four themes cut across the 4 KDE components:

Partnerships are key
Leveraging existing partnerships is a hallmark of KDE capacity. The types of partnerships can vary and include university research groups, provincial government ministries and departments, public health officers and non-governmental organizations:

> Another driver is the people who would link with us as a team. Relationships with the deputy and/or the minister, relationship with the school boards and the relationship with other research teams... building partnerships has been key (R; Prov).

Vision and strategic leadership
Building KDE capacity requires vision and strategic leadership. Youth Excel members expressed a need for a vision that is co-created and maintained over time and that resonates with all partners and stakeholders involved.

Language matters
Many Youth Excel members expressed the need to find and use common language. Terms and interpretations vary widely (e.g. for comprehensive school health and in knowledge translation) despite that individuals and organizations have invested heavily in creating common terms and concepts.

> One of the biggest [revelations] is communication and using common language... and although we are doing a lot of similar things, we tend to use different words or have different meanings behind the same words (R; Prov).

Thus, finding simple, common and universally understood language to communicate "building KDE capacity" is imperative.

> The differences between the language and priorities of research versus policy and practice are a challenge and it takes time and effort to work through and come to common agreement (R; Prov).

Funding/resources
Respondents talked about the importance of dedicated and sustained funding for all 4 components of KDE capacity. Responses on funding sources were mixed: some considered government commitment and funding in surveillance and evaluation crucial; others noted the importance of funding from outside government to facilitate sustainability of KDE capacity (i.e. "it can better weather the storm of government changes" [R; Prov]). Respondents also acknowledged the need for and opportunities to be creative with existing resources.

> What we are going to have to do is be more creative with what we have, reaching out to new partners to extend our capacity. It is about doing what we need to do more creatively (R; Prov).

Discussion

Systems approach

Results revealed new insights on building KDE capacity in Canada based on the analysis of a pan-Canadian initiative focused on youth aged 10 to 18 years. Five main insights are discussed.

First, the improvement cycle with 4 KDE components may help guide capacity-building efforts to strengthen KDE. The provisional model was relevant across several jurisdictions and sectors and helped Youth Excel members describe and stay focused on what they were trying to accomplish, both individually and collectively.

Second, Youth Excel provides some useful examples of how to translate the conceptual model of KDE into concrete and practical actions. Youth Excel demonstrated that a foundational asset for establishing priorities for action is a system for collecting and providing feedback, in this case on youth health behaviours at the local (school, community) level. In addition there is a need to learn about innovative interventions in the field. The results of these interventions need to be documented in a way that can be easily shared and the details (both "what" and "how") in particular should be easily adapted for use under other conditions. A mechanism for routine and continuous learning also needs to be in place. Effective mechanisms include community-, provincial/territorial- and/or national-level knowledge exchange forums that convene diverse stakeholders (i.e. researchers, practitioners and policy makers) across jurisdictions. These forums provide opportunities to share experiences, form partnerships, link people/groups together and leverage stakeholders' strengths and assets. Webinars are another cost-effective way to share experiences. Evaluation is required to generate new evidence that both establishes the effectiveness of interventions and guides their improvement. Results of these evaluations need to be distilled and shared, preferably using descriptive and memorable stories that can be easily told during webinars and provincial and/or national-level forums.

Third, the Youth Excel experience suggests the need for a systems approach to building KDE capacity. Results revealed a set of interdependent factors that accelerated or constrained the development of KDE capacity. Dominant factors included a shared vision, strategic leadership, a common language, frequent dialogue, partnerships and trust-building. These factors are most closely aligned with recent developments in knowledge translation* frameworks. In health, the dominant models have evolved over the past 15 years from linear models of knowledge flow to complex models that emphasize relationships and systems. The emphasis on principles and practices of evidence-based medicine (e.g. replication of specific interventions) has shifted to a stronger focus on organizational capacity and strategies,[12,13] sensitivity to context, [14,15] and a learning and change process that involves multiple perspectives (including research, policy and practice).[16-21] Systems models of knowledge transfer recognize that dissemination and implementation processes and relationships themselves are shaped, embedded and organized through structures that mediate the interactions among stakeholders with unique worldviews, priorities, languages, means of communication and expectations.[22] These stakeholders are tied together by a system that, in turn, is shaped by culture, structures, priorities and capacities.[13] This system requires activation if its various parts are to be linked together to connect knowledge to action.[23-25] This system activation may be the essence of Youth Excel.

Fourth, and consistent with a systems approach, Youth Excel offers insight into roles and relationships for partners from different jurisdictions. For example, the national organizations (JCSH and Propel) were well-positioned to efficiently support efforts within and across provinces compared with each province undertaking activities individually. Cases in point include the secretariat role served by Propel, CIMs, national forums and the peer learning exchange program. Provincial stakeholders were most suited to supporting KDE activities within and across local jurisdictions (e.g. regional health authorities) within their provinces. For example, provincial players co-ordinated surveys, convened provincial and local-level stakeholders for action planning in their province and tailored KDE components to their context. While local players were not formal members of Youth Excel, they were instrumental in all KDE activities and it is mostly local-level action that provincial and national-level organizations are enabling. The interplay across jurisdictions in Youth Excel provides some early insights into the need for a multi-level KDE system and examples of activities that can help to implement such a system.

Fifth, the Youth Excel experience shows that building KDE capacity takes time. At the end of 2011 and the 3 years of funding for Youth Excel, pan-Canadian KDE capacity for youth health was modest and highly variable across jurisdictions. Most significant developments were with local surveillance systems and related knowledge exchange, especially feedback reports for various audiences. Few developments were apparent for evaluation, and these evolved over a much longer time than the 3 years of Youth Excel; at the start of Youth Excel, some members had collaborated on various projects for as long as 16 years. Foundational assets like developing local data collection and feedback systems are complex undertakings and take a long time to develop.

Conclusion

Undertaking the future building of KDE capacity with a focus on youth health is both encouraging and sobering. It is encouraging that Youth Excel was able to deepen understanding of the complexities of KDE capacity and how to build it in diverse settings. Youth Excel was able to demonstrate through experience the importance of a systems approach to KDE[26] and how to translate a systems approach into assets and actions. An invaluable asset is the growing community in Canada that is committed to and acting to achieve a KDE *platform* that enables individual projects and interventions.

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* Many terms refer to the activities that link the production and use of knowledge, e.g. knowledge mobilization, knowledge exchange, knowledge to action. When referring to the general field, we use the expression "knowledge translation," consistent with the CIHR definition[27] as "a dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system."

What is sobering about the future is the work that remains to be done and the corresponding commitments needed from multiple jurisdictions (local, provincial, territorial, national) and players (research, policy and practice, health and education). Earlier work in the United States (with leadership from the Society for Prevention Research) came to similar conclusions about the need for community monitoring and feedback systems and the sustainable infrastructure to support these systems. Meeting these needs in Canada and abroad will allow us to achieve Youth Excel's vision of better evidence for use and better use of evidence in the service of youth health.

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Epidemiology of allergic rhinitis in Quebec: from a 2008 population-based survey

M. Canuel, MSc; G. Lebel, MSc

This article has been peer reviewed.

Abstract

Introduction: Our objective was to estimate the prevalence of symptoms and the proportion of a lifetime physician-based diagnosis of allergic rhinitis (AR) in the province of Quebec among people aged 15 years and older.

Methods: The 2008 Quebec Population Health Survey provided data on the prevalence of symptoms and proportion of lifetime physician-based diagnoses of AR. The prevalence of symptoms was defined as the proportion of individuals who, in the absence of a cold or the flu, had nasal and ocular symptoms in the 12 months before the survey.

Results: The reported prevalence of AR symptoms was 17%, although 9% did not have a diagnosed condition. Reported prevalence was lowest in those aged 65 years and older (12%) and was more common among women (19%) than men (15%). The estimated prevalence of lifetime physician-based diagnosis was 17%.

Conclusion: AR prevalence is high in Quebec with about 1 in 6 people experiencing symptoms. The condition is underdiagnosed and might also be undertreated.

Keywords: adult, allergic rhinitis, allergy, diagnosis, prevalence, rhinoconjunctivitis, symptoms

Introduction

Allergic rhinitis (AR) occurs as a result of exposure to allergens that induce inflammation of the nasal mucosa, causing nasal symptoms (e.g. sneezing, runny or blocked nose). The small size of some allergens (e.g. pollen) facilitates their penetration of the ocular mucosa causing ocular symptoms (e.g. itching, watering).

Many allergens are associated with AR symptoms and sensitization to these allergens differs between geographical regions. A United States study of 53 allergens showed that among atopic individuals, positive results were more frequent for graminae, tree pollen, dust mites and ragweed.[1] A similar investigation among people who consulted an asthma and allergy clinic in Québec City resulted in different findings, with allergic reactions more frequently linked to indoor allergens (e.g. dogs, cats and dust mites).[2] Allergic reactions to more than one allergen are common.[1,2] In the Calabria et al.[1] study cited above, the average number of positive tests per person among the 53 allergens tested ranged from 5 for 70- to 79-year-olds to 13 for 10- to 19-year-olds.

The prevalence of AR is increasing in several countries, especially in those with low or moderate rates.[3] We did not find any studies that estimated the prevalence of AR in adults in each region in Quebec. However, one investigation estimated the prevalence of AR symptoms in Montréal at 19% in 1995.[4] In Quebec, the main allergens responsible for AR symptoms are pollens. The Quebec Social and Health Survey of 1998 estimated that 10% of the Quebec population had hay fever (AR caused by pollen).[5]

The objective of our study was to estimate the prevalence of AR symptoms and the proportion of AR diagnosis in the province of Quebec among people aged 15 years and older.

Methods

Survey

The 2008 Quebec Population Health Survey (QPHS) was a questionnaire-based survey that collected information for the national surveillance plan. The survey, conducted by the Quebec Statistic Institute (QSI), covered different health matters and included 218 questions. The survey had a complex design, and the target population included people aged 15 years and older living in private households in Quebec. The sample size was chosen to obtain acceptable precision (coefficient of variation $\leq$ 15%) for a low prevalence of 2.8% at the regional level. The global response rate was about 58% with 38 154 people completing the telephone questionnaire, which was administered over 13 months (February 2008–March 2009) to take into account seasonal variation. The survey was representative of 6 326 523 people aged 15 years and older, corresponding to 97% of the population for that age group (two northern regions were excluded).[6]

Author references:

Institut national de santé publique du Québec (INSPQ), Québec, Quebec, Canada

Correspondence: Magalie Canuel, INSPQ, 945, avenue Wolfe, 4^e étage, Québec, QC G1V 5B3; Tel.: 418-650-5115, ext. 5224; Fax: 418-654-3144; Email: magalie.canuel@inspq.qc.ca

Questionnaire

Table 1 shows the QPHS questions on AR. Questions Q2 to Q5 were based on the validated International Study of Asthma and Allergies in Childhood (ISAAC) survey questionnaire. ISAAC is an international investigation that provides estimates of AR in children from nasal (Q2) and ocular (Q3) symptoms.[7,*] The QPHS also assessed the months during which symptoms flared (Q4) and limitations of daily activities (Q5). Questions Q6 and Q7, which are not from ISAAC, provide information on factors that trigger symptoms (pollen, animal allergens or dust mites) and on lifetime physician-based diagnosis. The questionnaire was available in French and English; 83% of the sample population spoke only French at home.[6]

Definitions

The prevalence of AR symptoms is defined as the proportion of individuals who answered "yes" to both Q2 and Q3, that is, those who reported nasal symptoms (sneezing, nasal congestion, runny nose) and ocular symptoms (itchy, watery eyes) in the absence of a cold or the flu. The prevalence of physician-based diagnoses of AR consists of individuals who answered in the affirmative to having been told by a physician that they had AR (Q7a), hay fever (Q7b) or a ragweed allergy (Q7c) during their lifetime (see Table 1).

We based the proportion of individuals who had seasonal symptoms (i.e. over 1 to 6 months, continuous or not) as opposed to those who had perennial symptoms (i.e. over 7 months) on answers to Q4.

Statistical analysis

The Quebec Public Health Infocentre provided data for this study using SAS version 9.1 statistical software (SAS Institute Inc., Cary, NC, US) and the 2008 QPHS database. The Infocentre provides online access to standardized results of indicators defined in the surveillance plan to public health stakeholders.

The QSI used the hot deck imputation method to impute the respondent's age (3% of missing data) and a linear regression model to impute the household category of income (32% of missing data). All percentages were weighted to represent population estimates. As a result, we do not show sample sizes in this manuscript. Proportions had coefficients of variation of 15% or less unless otherwise stated. Because of the complex sampling design, bootstrap weights, provided by QSI, were used to estimate unbiased precisions on proportion[8] and to estimate 95% confidence intervals (CIs) using the 2.5 and 97.5 percentile of the 2000 bootstrap weights distribution. Bootstrap weights were also used in comparing two proportions. First, the difference between the two proportions was calculated for the 2000 bootstrap weights. The differences in the 2000 proportions were placed in order and a 95% CI with the 2.5 and 97.5 percentiles of the difference distribution built. The difference between two proportions was deemed statistically significant if the CI did not include the null value.

Non-response was estimated as the weighted ratio of the number non-responders to the total number of subjects. Data in this manuscript are mainly descriptive: no adjustment was made for age or gender.

Results

Prevalence of allergic rhinitis symptoms

In 2008, 17% of the Quebec population 15 years and older had symptoms of AR during the previous 12 months. The prevalence was significantly lower (12%) in

TABLE 1
English version of questionnaire on AR in the Quebec Population Health Survey, 2008

Question		Available answers
Q2	In the past 12 months, that is, the period beginning on (date 12 months ago) and ending yesterday, did you have episodes of sneezing, or have a dripping or stuffy nose when you did not have a cold or flu?	Yes / no (go to Q7a) / does not know (go to Q7a) / no response (go to Q7a)
Q3	In the past 12 months, were these nasal problems accompanied by watery and itchy eyes?	Yes / no
Q4	During which month or months over the past 12 months did you have these nasal problems?	January; February; March; April; May; June; July; August; September; October; November; December; All the months of year
Q5	During the past 12 months, did these nasal problems limit your daily activities?	Not at all / a little / somewhat / a lot
Q6	Did the following elements usually trigger or increase these nasal problems? a) Dust mites or house dust; b) Pollen; c) Animals; d) Are there other elements (causes) that usually trigger or increase these nasal problems? If yes, Specify.	Yes / no
Q7	Has a doctor ever told you that: a) You have allergic rhinitis? b) You have hay fever? c) You are allergic to ragweed?	Yes / no

[*] ISAAC includes ocular symptoms as part of its assessment of AR.

TABLE 2
Prevalence of AR symptoms and proportion of physician-diagnosed AR in the Quebec population, ≥ 15 years, by age and sex, 2008

Characteristics	AR symptoms in previous 12 months		Lifetime physician-diagnosed AR	
	% (95% CI)	Non-response, %	% (95% CI)	Non-response, %
Age, years[a]				
15–24	16.1 (14.2–18.3)	0.8	17.3 (15.3–19.5)	1.6
25–44	19.6 (18.3–20.9)	0.9	20.9 (19.5–22.2)	1.7
45–64	16.8 (15.8–17.9)	0.9	16.2 (15.2–17.3)	1.9
≥ 65	11.8 (10.5–13.0)	1.6	9.2 (8.1–10.4)	2.5
Sex, n[b]				
Women	19.1 (18.1–20.0)	0.9	18.3 (17.4–19.3)	2.1
Men	14.5 (13.5–15.5)	1.1	15.3 (14.3–16.3)	1.6
Total	**16.8 (16.2–17.5)**	**1.0**	**16.8 (16.1–17.5)**	**1.9**

Abbreviations: AR, allergic rhinitis; CI, confidence interval.

[a] Differences for all age groups are statistically significant except for 15–24 and 45–64 year age groups.

[b] Differences in prevalence between all pairs are statistically significant.

the elderly (≥ 65 years), and significantly higher in women (19%) than in men (15%) across all age groups (Table 2).

The prevalence of AR symptoms increased significantly with education level, from 13% among those with no high school diploma to 16% for those who had completed high school and 19% for those who had completed college or university (19% and 20%, respectively) (Table 3).

The difference in prevalence of AR symptoms in income quintiles was not statistically significant (Table 3).

Other features of allergic rhinitis among people with symptoms

The survey asked respondents which month or months in the previous 12 they had experienced AR symptoms. The proportion with symptoms during the summer (June, July or August) was the highest (50%), followed by those with symptoms in spring (March, April or May; 41%). The proportion was lowest (12%) in winter (December, January or February) (Table 4).

The most frequently reported allergen among the 3 triggers listed was pollen (76%), followed by dust mites (55%) and animal allergens (40%). Over 64% reported at least 2 triggering factors, while 31% reported only 1 (Table 4).

TABLE 3
Prevalence of AR symptoms in the previous 12 months in the Quebec population, ≥ 15 years, by level of education and income, 2008

	AR symptoms in previous 12 months	
	% (95% CI)	Non-response, %
Education[a]		
< Secondary school	12.8 (11.7–13.9)	1.4
Secondary school graduate	15.6 (14.4–16.8)	1.1
College graduate	19.2 (17.8–20.7)	0.8
University graduate	19.8 (18.2–21.5)	0.6
Income		
1st quintile (low)	16.4 (14.8–18.2)	1.0
2nd quintile	16.0 (14.6–17.5)	1.5
3rd quintile	17.6 (16.0–19.2)	0.9
4th quintile	17.0 (15.4–18.6)	0.5
5th quintile (high)	18.0 (16.4–19.7)	0.5
Total	**16.8 (16.2–17.5)**	**1.9**

Abbreviations: AR, allergic rhinitis; CI, confidence interval.

[a] Differences between all groups are statistically significant except those with college and university degrees.

The symptoms of the majority (77%) of people with AR did not limit them in their daily activities. However, 9% were moderately or severely limited in their daily functions (Table 4).

The majority of people with AR had seasonal symptoms, either over a consecutive or non-consecutive period of 1 to 3 months (61%) or 4 to 6 months (16%). Just under a quarter (23%) had perennial symptoms (7 to 12 months) (Table 4).

Lifetime prevalence of physician-based allergic rhinitis diagnosis

The lifetime prevalence of a physician-based diagnosis of AR in the study population 15 years and older was 17%. Prevalence was higher in women (18%) than in men (15%), and also higher in 25- to 44-year-olds (21%) and lower in those aged 65 years or over (9%) (Table 2).

Comparison between prevalence of symptoms and prevalence of physician-based allergic rhinitis diagnosis

We observed that individuals who had symptoms of AR (17%) were not necessarily the ones who had a physician-based diagnosis of AR (17%) (Figure 1). Only

TABLE 4
Distribution of the study population, ≥ 15 years, with AR symptoms in previous 12 months, Quebec, 2008

	Distribution of population with AR symptoms	
	% (95% CI)	Non-response, %
Season[a]		6.9
Summer (June, July, August)	49.9 (47.5–52.1)	
Spring (March, April, May)	41.3 (39.1–43.5)	
Fall (September, October, November)	30.2 (28.1–32.3)	
Winter (December, January, February)	12.1 (10.6–13.5)	
Triggers[a]		
Pollen	75.5 (73.4–77.5)	6.0
Dust mites	55.5 (53.1–57.7)	8.8
Animal allergens	40.0 (37.7–42.4)	5.2
Number of triggers[b,c]		15.2
1	31.0 (28.7–33.3)	
2	29.6 (27.5–31.8)	
≥ 3	34.7 (32.3–37.0)	
Limitation of daily activities[d]		1.3
Not at all	77.2 (75.3–79.0)	
A little	13.6 (12.1–15.3)	
Somewhat	6.3 (5.3–7.3)	
A lot	2.9 (2.2–3.7)	
Duration[d]		6.9
Seasonal: 1–3 months	60.5 (58.3–62.6)	
Seasonal: 4–6 months	16.2 (14.7–17.9)	
Annual: 7–12 months	23.3 (21.6–25.2)	

Abbreviations: AR, allergic rhinitis; CI, confidence interval.

[a] No statistical test was performed.

[b] From a list of 3 triggers and open response to others.

[c] Only 2 categories are statistically different, i.e. 2 and ≥ 3 triggering factors.

[d] Differences between all pairs are statistically significant.

7% of the study population had symptoms and had ever been diagnosed with AR; 9% had symptoms but no diagnosis. Another 10% had a physician-based diagnosis without declaring any symptoms during the previous 12 months. When these proportions are combined, the true prevalence of AR could be as high as 26% (9% + 7% + 10%) (Figure 1).

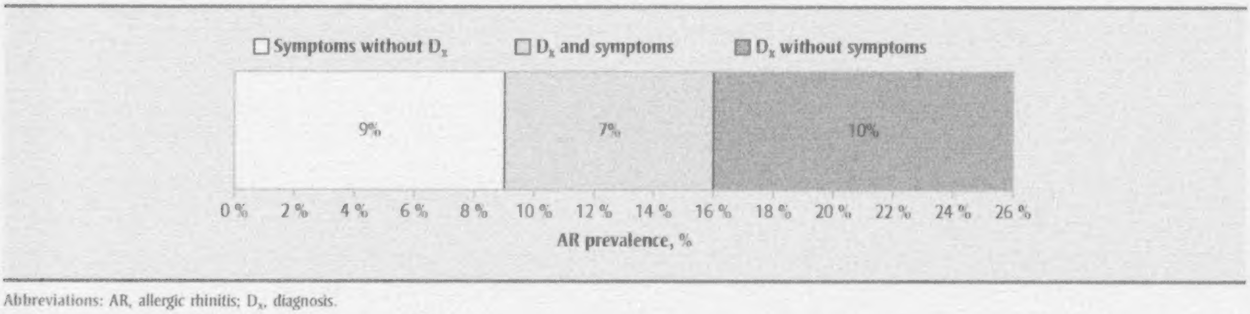
Discussion

The 2008 QPHS is the most comprehensive survey conducted on AR in Quebec. The results are also representative of the population of individuals aged 15 years and older in this province. However, the survey did not include residents in residential care who generally have a poor physical health. This may result in underestimating the prevalence of some diseases. Nevertheless, we have no reason to believe that the prevalence of AR would be higher in the excluded population.

Non-responses to most questions were less than 5%. In those cases, the risk of bias is considered low. Non-response was higher for questions on months of symptoms (season and duration) as well as for the triggers. Non-response for AR timing might be as a result of a memory bias as the person had to recall symptoms over the previous 12 months. For triggering factors, including the number of allergens, the non-respondents might be unaware of their AR triggers. This may be because of the high proportion of undiagnosed individuals since clinical tests scheduled as a result of medical diagnoses often identify the triggering factors.

Although both the prevalence of symptoms and that of lifetime physician-diagnosed AR were similar (17% each), our analysis showed that only 7% of the population

FIGURE 1
Combined AR prevalence of people with symptoms in previous 12 months and those who received a lifetime physician-based diagnosis of AR, Quebec, 2008



Abbreviations: AR, allergic rhinitis; D_x, diagnosis.

with symptoms had ever had a physician diagnose their AR. The proportion of undiagnosed AR was estimated to be 56% among those with symptoms, which corresponded to 9% of the study population 15 years and older with undiagnosed AR. This situation may be explained in part by the fact that over-the-counter medication to treat symptoms of AR is readily available and people who have symptoms can receive advice from their pharmacist.

Around 10% of the population aged 15 years and older who were asymptomatic in the previous 12 months had been diagnosed as having AR by a physician. This lack of symptoms may be because their physicians advised them of preventive and protective measures, including reducing exposure to allergens, or on treatment (e.g. intranasal glucocorticosteroids, immunotherapy).[9]

The measure of the proportion of people with an AR diagnosis underestimates the true prevalence of AR as 9% had symptoms without ever having a positive diagnosis. On the other hand, the measure of the prevalence of symptoms also underestimates the true prevalence of AR as 10% of our study population had been diagnosed despite not having any symptoms. Combining these two proportions may provide a better picture of AR in Quebec. The proportion of physician-diagnosed AR in our population was 17%, but the true prevalence of AR could have been as high as 26% when we include those with symptoms but no physician-based diagnosis. This proportion is similar to an estimate of 17% to 29% (depending on the country) based on the results of a survey with clinical testing performed in five European countries.[10] However, some non-allergic conditions such as infections, hormonal imbalance and exposure to physical agents can cause similar ocular and nasal symptoms,[9] indicating that the prevalence of AR, symptomatic or otherwise, is unlikely to be as high as 26%.

Our results showed that the prevalence of AR symptoms increased with level of education. We cannot explain the reason for this. In Canada, income is associated with level of education.[11] Nevertheless, the prevalence of AR symptoms did not vary significantly with income. Most studies tested socioeconomic status and one estimated a lower prevalence of allergies among people with lower education status in the United States in 1978.[12] Misunderstanding questions is unlikely to have been the reason for any errors among survey respondents since our questions were based on the French and English versions of the ISAAC children's questionnaire and our respondents were aged 15 years and older.

Although most studies found the prevalence of AR to be higher in children and youth (i.e. those aged 16-24 years),[13] others found prevalence to be higher in older age groups, [1,14] as did we among 25- to 44-year-olds.

Pollen (76%) was the allergen most often reported as the factor triggering survey respondents' symptoms. Similarly, Schatz[15] found pollen to be the triggering factor among 78% of those with physician-diagnosed AR in the United States. We found that 64% of people with AR symptoms reported more than one triggering factor, which is similar to results from another Quebec study that found that 53% of people with allergies had skin reactions to more than one allergen.[2]

We found the proportion of people limited in their daily activities by symptoms of AR (23%) to be similar to that estimated in the United States (15%-25%)[16] where it was also found that 38% of people with AR could not tolerate their symptoms without using some medication.[16] Schatz[15] found that half of those diagnosed with AR could not control their symptoms, even though most took at least 2 different medications. In Quebec, the cost associated with AR associated with ragweed was estimated at $156 million, of which $33 million were spent on medications.[17]

Conclusion

AR is common in Quebec, affecting at least 17% of the population aged 15 years and older. It is underdiagnosed and might be undertreated, as 16% of people with AR symptoms had seasonal symptoms over a period of 4 to 6 months. This is the first survey to estimate AR prevalence in Quebec and our results are not comparable to other Quebec surveys that mainly focused on hay fever. The combined prevalence of symptoms and lifetime physician-based diagnosis of AR estimated in this study should provide a baseline for future investigations in the same population.

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Short Communication

The role of animal-sourced insulin in the treatment of type 1 diabetes and its availability

A. V. Klein, MD, DPH; E. Taylor, MD, CCFP, FCFP; C. Legaré, MD, CCFP Cert PE & PV; D. Vu, PhD; E. Griffiths, PhD

This article has been peer reviewed.

Abstract

As a result of a number of factors, the treatment of insulin-dependent diabetes has moved away from using insulin of beef or pork origin to using recombinant (biosynthetic) insulin preparations. However, some people with type 1 diabetes can manage their diabetes better using animal-sourced insulin. Despite dwindling options and decreased production, animal-sourced insulin—and pork insulin in particular—is still available on the Canadian market.

This communication describes the actions taken by Health Canada with respect to the availability of animal insulin.

Keywords: *insulin, pork insulin, beef insulin, recombinant insulin, biosynthetic insulin, type 1 diabetes*

Introduction

The discovery that insulin controls blood sugar was a vital contribution to the treatment of diabetes mellitus. Insulin has not only saved lives, it has also allowed most people with diabetes to live a relatively normal life. In its early days, insulin was extracted from bovine and porcine pancreases. However, a number of complex factors have resulted in a decline in the use of animal-sourced insulin. These factors include the development of recombinant (biosynthetic or rDNA-derived) insulin preparations with various lengths of activity; the emergence of prion diseases, most notably Bovine Spongiform Encephalopathy or "mad cow disease" in cattle, and the dwindling of beef insulin production and supply as a consequence; constant threats of a shortfall of animal pancreases used to produce an adequate supply of insulin; and other less clear factors.

Current situation

Biosynthetic (recombinant) insulin, which is structurally similar to endogenously secreted insulin, was developed with the expectation that an insulin very similar to human endogenous insulin would neither cause immunological phenomena or elevate serum IgG levels, specifically in people with type 1 diabetes. However, over the past decade, some of those who contacted Health Canada reported that they experienced frequent and severe hypoglycemic episodes when undergoing treatment with biosynthetic insulin. In addition, these patients' glycemic control was more even and consistent and they generally felt better and healthier while on insulin of animal origin. Health Canada also noted that some people reported that their level of antibodies in response to the biosynthetic insulin was higher than that to pork insulin and, more particularly, to beef insulin. Let's recall that the immunogenicity of biosynthetic insulin is similar to that of highly purified pork insulin, to which it is considered clinically equivalent.

Hypoglycemia is the most common adverse effect of all insulin products, regardless of their type or origin. In certain cases—long duration of diabetes mellitus, the presence of diabetic neuropathy, the very strict control of diabetes mellitus, recurrent exposure to severe hypoglycemia or the age of the patients—the nature and intensity of the early warning signs of hypoglycemia (pallor, sweating, anxiety, headache, tachycardia and hunger) may be less pronounced. Hypoglycemia may also occur without recognizable symptoms and lead to confusion, loss of consciousness and/or convulsions.[1]

Impaired awareness of hypoglycemia, which may develop regardless of whether animal or biosynthetic insulin is used,[2] affects approximately 25% of people with type 1 diabetes.[3] Rates of severe hypoglycemia that require external assistance, that is, the administration of glucagon to raise blood glucose levels, are 5.1 times higher in those with impaired hypoglycemia awareness and 9.6 times higher in those with hypoglycemia unawareness.[4,5]

A systematic review conducted in 2005 and updated in 2009 "to assess the effects of different insulin species by evaluating their efficacy (in particular glycaemic control) and adverse effects profile (mainly hypoglycaemia)" showed no rele-

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Author reference:

Health Products and Food Branch, Health Canada, Ottawa, Ontario, Canada

Correspondence: Agnes V. Klein, Centre for Evaluation of Radiopharmaceuticals and Biotherapeutics, Biologics and Genetic Therapies Directorate, Health Products and Food Branch, Health Canada, 200 Tunney's Pasture Drive, AL 0700C, Ottawa, ON K1A 0K9; Tel.: 613-954-5706; Fax: 613-946-0639; Email: agnes.v.klein@hc-sc.gc.ca

vant clinical differences in either efficacy or adverse reactions between the different insulin preparations. However, high quality randomized clinical trials examining outcomes such as health-related quality of life or diabetic complications were never conducted.[6,7]

An Expert Advisory Panel on Insulin was convened to help Health Canada learn about the benefits of animal-sourced versus biosynthetic insulin as well as about labelling the insulin preparations.[8] One of the Panel's recommendations was to improve communications about the insulins of diverse origins. In addition, the Panel recommended that Health Canada continue to make animal-sourced insulins available for those patients with type 1 diabetes mellitus who achieve better metabolic control with this type of insulin; doing so is in keeping with the International Diabetes Federation's 2005 position statement on animal, biosynthetic and analogue insulins, which notes that no single insulin type will suit every person, and that maintaining a variety of insulins from which to select one that suits each patient best is ideal.[9] At the same time, the Panel noted that further research may be needed to elucidate the differences seen in/by certain patients when they use insulin of animal origin as opposed to biosynthetic/recombinant forms of insulin.

Actions by Health Canada

Health Canada has undertaken a number of the activities recommended by the Expert Panel on communicating with the public and health professionals about animal-origin insulin, although the majority fall outside the direct responsibility and mandate of its regulatory arm. Health Canada has updated the product monographs for all marketed insulin products and, with the Public Health Agency of Canada, updated existing fact sheets on insulin and diabetes so as to include information about animal-sourced insulin.[10]

Health Canada acknowledges that pharmaceuticals are a shared responsibility between the federal, provincial and territorial governments. From the regulatory perspective Health Canada will continue to communicate on the subject of animal insulin as needed, while respecting that drug coverage and the listing of treatments on formularies for reimbursement is a provincial and territorial responsibility. In addition, Health Canada has informed relevant stakeholders of the Panel's recommendations and is encouraging the adoption of these, including continued research to address the data gaps identified by the Panel.

Physicians can continue to prescribe Hypurin® Pork Regular and Neutral Protamine Hagedorn (NPH) insulin preparations, manufactured by Wockhardt UK Ltd., which continue to be marketed in Canada. Federal, provincial and territorial drug plans have processes to evaluate requests for compassionate access to animal-sourced insulin.

Beef insulin may also be obtained from Wockhardt UK, subject to availability, via Health Canada's Special Access Programme. Laboratorios Beta S.A. in Argentina produces some beef and pork insulin but they have neither obtained market authorization nor made their supply available in Canada.

Conclusion

Despite the shift towards biosynthetic insulin in the treatment of type 1 diabetes in Canada, the need for animal-sourced insulin remains. There is some evidence to suggest that some patients have better metabolic and symptomatic control when receiving animal-sourced insulin and can therefore manage their diabetes more effectively. As a result, animal-sourced insulin remains available in Canada as a treatment option for health care professionals and patients. Given the need for animal-sourced insulin, Health Canada will continue to monitor the situation and work with stakeholders and manufactures on the place in therapy and the availability of animal-sourced insulin in Canada.

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Report Summary

Seniors' Falls in Canada: Second Report: key highlights

A. Stinchcombe, PhD; N. Kuran, MA; S. Powell, MA, MSW

Introduction

Injury in Canada is a serious public health concern. Injuries are a leading cause of hospitalization for children, young adults and seniors and a major cause of disability and death.[1] Falls remain the leading cause of injury-related hospitalizations among Canadian seniors, and data from the Canadian Community Health Survey – Healthy Aging indicate that 20% of seniors living in the community reported a fall in the previous year, with a higher prevalence among older seniors, i.e., those aged over 80 years.[2] Falls and associated outcomes not only harm the injured individuals but also affect their families, friends and care providers; they also place considerable pressure on the health care system. However, we do know that these personal and economic costs can be avoided through injury prevention activities.

The *Seniors' Falls in Canada: Second Report*[3] provides policy makers, researchers, community programmers and practitioners with current data and trends on falls, injuries and hospitalizations among Canadian adults aged 65 years and over. This report is intended for use in public health research, policy development and practice.

The data used in the *Seniors' Falls in Canada: Second Report* were taken from the Canadian Community Health Survey (annual), the Hospital Morbidity Database and Canadian Vital Statistics. These data show an increasing need for effective fall interventions initiatives targeted at older adults. Falls can lead to negative mental health outcomes such as fear of falling, loss of autonomy and greater isolation, confusion, immobilization and depression. In addition to the negative physical and mental health consequences of falling, the significant associated financial costs are estimated at $2 billion annually, which is a value 3.7 times greater than that for younger adults.[4]

Select results

- The number of self-reported injuries due to falls increased by 43% between 2003 and 2009/2010 (Figure 1). Rates of fall-related injuries continue to be higher among older females compared with older males (Figure 2). The majority of falls resulted in broken or fractured bones, and over one-third of fall-related hospitalizations among seniors were associated with a hip fracture. The frequency of injury and resulting care implications highlights the impact of falls on older adult themselves and their caregivers, as well as the pressure on Canadian health care systems.
- While fall-related hospitalizations increase with age in both men and women, these rates are higher in women (see Figure 3). Moreover, seniors hospitalized for a fall remain in hospital on average 10 days longer than those hospitalized for any cause. This discrepancy highlights the disproportionate health care costs of fall-related injuries in comparison to other causes of hospitalization.
- Canadian data revealed that the number of deaths among seniors due to falls increased by 65% from 2003 to 2008 (Figure 4). The frequency of deaths and the age-standardized mortality rates due to falls were highest among the oldest seniors.

Risk factors and best practices

Risk factors for falls in seniors are numerous, complex and interactive. These factors are categorized as biological/intrinsic, behavioural, environmental and social/economic. Each older person may face a unique combination of risk factors according to his or her life circumstances, health status, health behaviours, economic situation, social supports and environment. Factors that put seniors at risk of falls include chronic and acute health conditions and their pharmacological treatment, balance or gait deficits, sensory factors, inadequate nutrition and social isolation as well as factors related to the built and social environment.

As our population ages, efforts will need to be re-focused on falls prevention to maintain and improve the quality of life and well-being of seniors and to ensure that they continue to contribute to and participate in society. Preventing falls requires interventions that target more than one risk factor. Specifically, the evidence supports comprehensive individual assessment followed by multifactorial, evidence-based practices. Falls prevention guidelines may be useful to assess individual risks, behaviours and challenges and establish standards that minimize the number and impact of falls. Further, interventions need to be tailored to the individual's health status, situation and environment.

The research literature on risk factors for falls and on best practices in falls prevention reveals a number of research gaps. In particular, there is a lack of knowledge around the efficacy of falls prevention practices for subpopulations of Canadian seniors. Given that 50% of falls that result in hospitalization occur in the home and the

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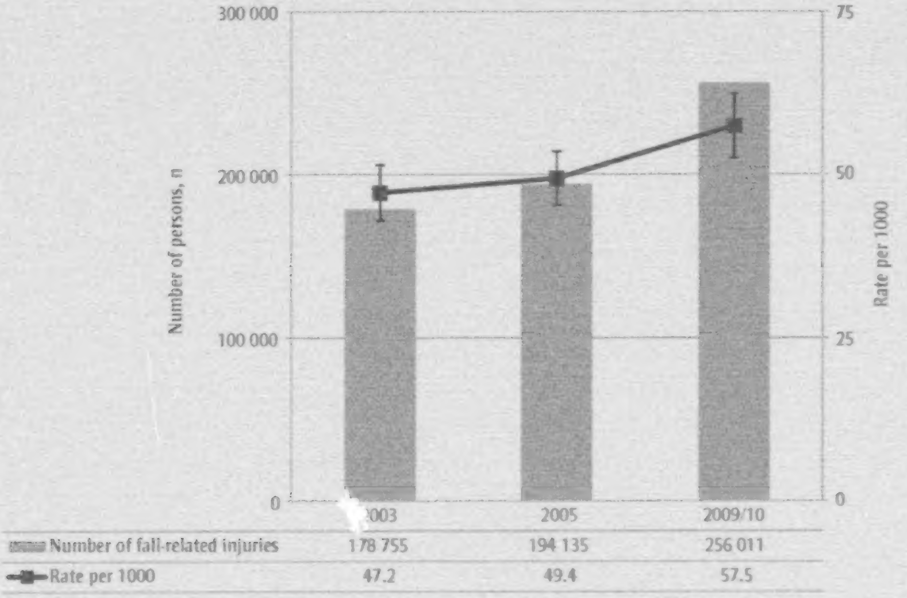
Author reference:

Division of Children, Seniors and Healthy Development, Public Health Agency of Canada, Ottawa, Ontario, Canada

FIGURE 1

Estimated number of cases and rates (per 1000, with 95% confidence intervals) of injuries resulting from a fall, age ≥ 65 years, Canada, 2003, 2005, 2009/2010

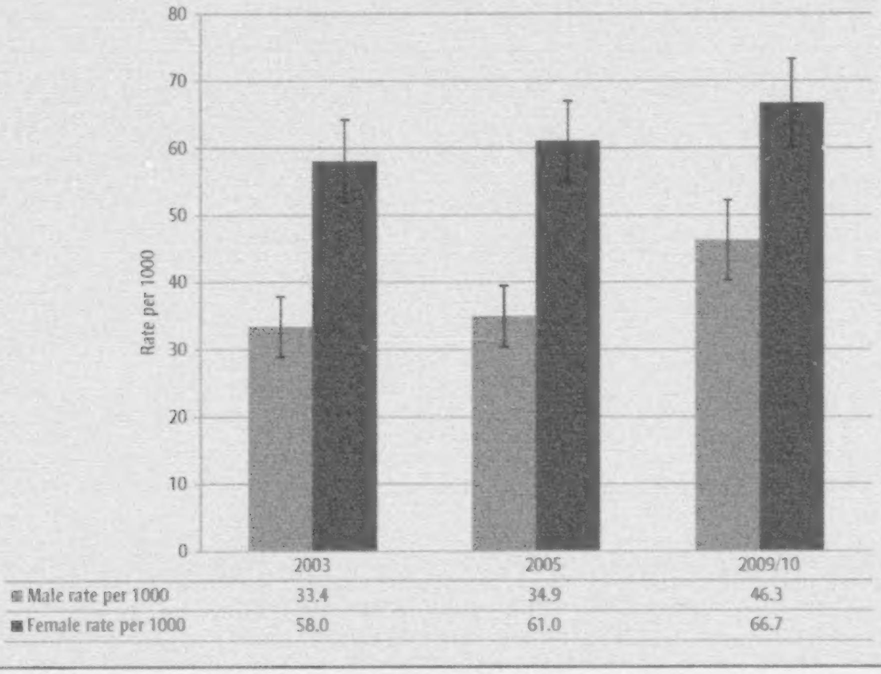


	2003	2005	2009/10
▨ Number of fall-related injuries	178 755	194 135	256 011
■ Rate per 1000	47.2	49.4	57.5

Source: Canadian Community Health Survey, Share Files, Cycle 2.1 (2003), Cycle 3.1 (2005) and 2009/10.

FIGURE 2

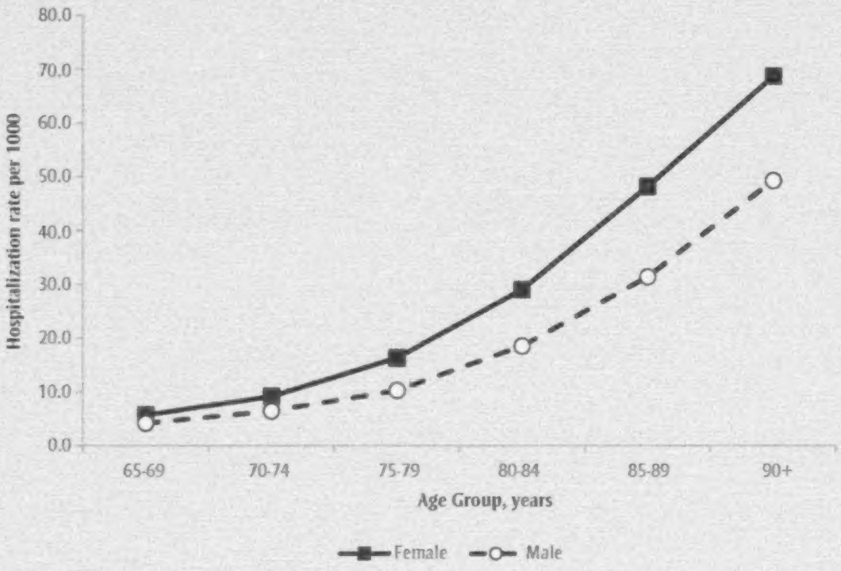
Estimated rates (per 1000, with 95% confidence intervals) of injuries resulting from a fall, by sex, age ≥ 65 years, Canada, 2003, 2005, 2009/10



	2003	2005	2009/10
▨ Male rate per 1000	33.4	34.9	46.3
■ Female rate per 1000	58.0	61.0	66.7

Source: Canadian Community Health Survey, Share Files, Cycle 2.1 (2003), Cycle 3.1 (2005) and 2009/10.

FIGURE 3
Fall-related hospitalization rates, by sex and age group, age ≥ 65 years, Canada, 2010/11



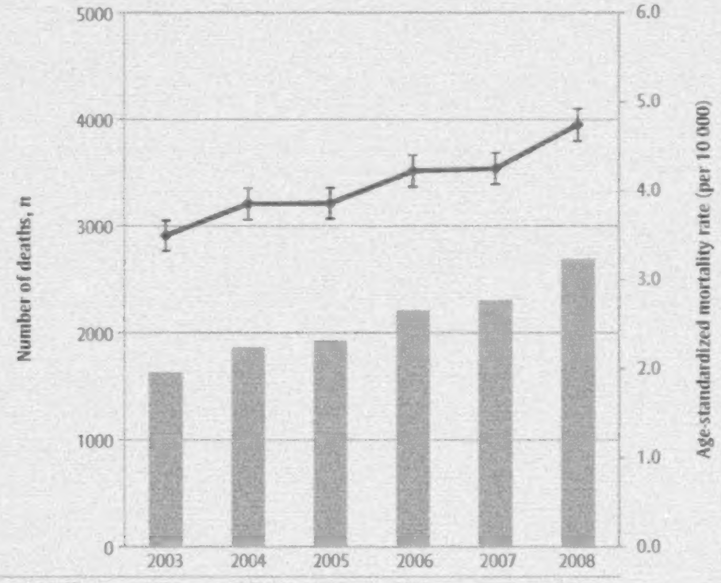
Source: Canadian Institute for Health Information, Hospital Morbidity Database, 2010/11.

same percentage of seniors are discharged back to a home setting, the report also serves to highlight the importance of developing and evaluating tools for seniors and their families to plan for safely aging in place.

Conclusion

Over the years, Canada has laid a foundation for good health and well-being across the life course. Healthy aging is about creating conditions that allow individuals to continue to make choices and thrive. Falls among seniors are largely preventable; however, their multifactorial nature means that addressing this growing public

FIGURE 4
Number of deaths and age-standardized mortality rate (with 95% confidence intervals) due to falls, age ≥ 65 years, Canada, 2003–2008



	2003	2004	2005	2006	2007	2008
▨ Number of deaths, age ≥ 65	1631	1869	1925	2210	2305	2691
◆ Age-standardized mortality rate	3.5	3.9	3.9	4.2	4.2	4.7

Source: Statistics Canada, Vital Statistics, 2003–2008.

health problem is a shared responsibility. Progress in preventing falls and the resulting injuries requires continued multisectoral collaboration between governments, health care providers, non-governmental organizations, care associations and services as well as Canadians themselves.

The full report is available online[3] at http://www.phac-aspc.gc.ca/seniors-aines/publications/public/index-eng.php. The Public Health Agency of Canada will use the report as the basis for continued and detailed analysis. Further reports that examine the effects of gender and age differences on those who fall, as well as on falls by place of residence other than long-term care, would be useful.

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Letter to the Editor

Canadian tritium study misleading to the public

Re: "Estimating cancer risk in relation to tritium exposure from routine operation of a nuclear-generating station in Pickering, Ontario" by S. Wanigaratne, E. Holowaty, H. Jiang, T. A. Norwood, M. A. Pietrusiak, P. Brown (Chronic Diseases and Injuries in Canada, Vol 33, No 4, September 2013, p. 247–56).

Dear Editor,

We believe that the conclusions of the article are misleading due to limitations of the study.

All doses discussed in the study are estimates, based on hypothetical data, assumptions, modelling and standardized human physiology (ignoring the large variation of size/weight, metabolism, ethnicity and genetic radiosensitivity of the population). There are no actual measurements of tritium for any cohort members. There is much controversy as to the accuracy of these dose estimates, and true doses to local people may be manyfold higher.

Tritium emissions from the Pickering nuclear reactor are high (based on levels obtained from Ontario Power Generation via access to information). It is surprising that the estimated doses to the public are deemed to be so low in this study. The recent situation surrounding tritium sampling at the Shield Source Incorporated plant in Peterborough does not instill confidence in the Canadian Nuclear Safety Commission (CNSC)'s accuracy in measuring emissions. The stack sensor was found, after 18 years of operation and several CNSC inspections, to be under-reporting by close to a factor of 10.

Children under 5 years old are not included in this study. This is a serious omission as some research has shown higher rates of leukemia in children under 5 who live in close proximity to a nuclear reactor.[1] The finding of an almost double risk of cancer in girls age 6 to19 years is very concerning. Tritium should not be dismissed as a cause because of the low dose estimates. It is theoretically possible that very tiny doses of tritium, incorporated into developing tissues in the fetus, could be enough to initiate a cancer in a child. Of note, there are many other carcinogenic radionuclides emitted from nuclear reactors, none of which have been addressed in this study.

The authors' effort to include a cohort of "non-movers" exposed to "stable tritium" is admirable, but 6 years is too short an interval to ascertain the effects of tritium exposure, which can cause cancer after a latency of several decades.

The choice of control group is problematic for two reasons: 1) incomes in this group (North Oshawa) are on average $10 000 lower than the Pickering group, which places the control group in a different, and potentially less healthy, demographic; and 2) North Oshawa is between the Pickering and Darlington reactor complexes. Given that tritium has a half-life of 12.3 years and will be circulating in the environment for several times that long, it is not a fair assumption that this population is not exposed.

The authors do not mention that there is much uncertainty regarding the half-life of organically bound tritium, which they claim is 48.5 days. Some scientists estimate the half-life to be as much as 500 days, which means even small amounts would accumulate over many years of exposure.

The study is underpowered and has significant limitations. Ontarians should not be reassured by the study's conclusion that people living in the vicinity of nuclear power plants in Ontario do not have elevated cancer risk due to tritium emissions.

Cathy Vakil, MD, CCFP, FCFP
Assistant Professor, Department of Family Medicine, Queen's University, Kingston, Ontario, Canada

Linda Harvey, BSc, MSc, MD
President, Physicians for Global Survival, Ottawa, Ontario, Canada

Reference

1. Kaatsch P, Spix C, Schulze-Rath R, Schmiedel S, Blettner M. Leukaemia in young children living in the vicinity of German nuclear power plants. Intl J Cancer. 2008;122(4):721-6.

Authors' response

The authors would like to thank Drs. Cathy Vakil and Linda Harvey for their letter regarding our study "Estimating cancer risk in relation to tritium exposure from routine operation of a nuclear-generating station in Pickering, Ontario."

Drs. Vakil and Harvey believe that our conclusions are misleading given the study's (acknowledged) limitations. However, we stand by our conclusions that tritium estimates were not significantly associated with increased risk of radiation-sensitive cancers in Pickering.

Firstly, we have not misrepresented the tritium estimates used in our regression models as individual dose estimates, as Drs. Vakil and Harvey seem to suggest. We do not refer to our tritium estimates as "tritium dose" for this specific reason. We have clearly stated that our estimates of tritium are modelled from real tritium emissions data (rather than "hypothetical" data as Drs. Vakil and Harvey suggest) and are indeed based on standard and accepted environmental, chemical and biological assumptions. Exposure assessment in environmental epidemiology is a difficult task, as explained by Rothman,[1] and would be prohibitively expensive and laborious if long-term individual monitoring and measurements were the only option. Faced with these difficulties, public health researchers attempting to address valid community concerns about health effects of environmental exposures often turn to proxies for such information. To the best of our knowledge, all previously published studies examining the relationship between radiation exposure from nuclear power generation and cancer either assumed exposure based on location or used distance-to-the-source as a proxy for exposure, a method that is likely to misclassify radiation exposures. The German study (Kaatsch et al[2]) referenced by Vakil and Harvey used this method. Given the advances in geographical and mathematical modelling methods used to estimate environmental exposures, and the acceptance of these methods in the scientific community,[3] we are justified in choosing this method to estimate tritium exposure for the Pickering cohort. We have stated that our modelled tritium estimates are consistent with that of on-site radiation monitors near the Pickering Nuclear Generating Station (PNGS). We also fully acknowledged that we are less confident that these estimates represent true dose to cohort members. We accept that modelled tritium estimates may not be the ideal method but we must emphasize that it improves on using location or distance-to-the-source as a proxy for exposure. Based on this method of tritium estimation, our findings clearly do not support a significant association between tritium estimates and increased cancer risk.

Drs. Vakil and Harvey found it surprising that our modelled tritium estimates translated to very low dose estimates. We reiterate that the average effective dose based on our modelled tritium estimates was calculated to be 0.47 μSv/year (range: 0–2.36 μSv/yr). This is several orders of magnitude lower than the typically referenced low-dose range (1000–100 000 μSv/yr),[4] and lower than both the annual dose from natural background radiation near PNGS (1338 μSv/yr)[5] and the 50 μSv radiation dose received from a chest x-ray.[6] If emissions data were under-reported by a factor of 10, as suggested by the example given by Vakil and Harvey, this would still translate into effective doses lower than levels of concern.

As to the assertion that we omitted children under 5 years old from our study, as we stated in our methods section, the property assessment file that was the data source for our cohort suffered from undercounting of the population aged less than 5 and over 85 years of age. For this reason, we were unable to draw any conclusions about cancer risk for those under 5 years of age. With respect to the findings of Kaatsch et al,[2] an editorial by Little et al[7] suggested that chance is the most likely explanation for the increased risk of leukemia observed in children under five years of age living near German nuclear power plants (NPPs). In addition, an interdisciplinary working group of international scientists (The Commission on Radiological Protection) was charged with evaluating that study's findings and concluded that increased cancer risk was not causally related to radiation emitted from NPPs.[8]

The finding of doubled cancer risk among girls aged 6 to 19 years should be a concern only if we were unable to find a reasonable explanation. However, we have highlighted several possible reasons for this finding, the most likely of which is the chance nature of the finding given multiple testing.

For clarification, our non-mover cohort was stable in terms of residential location for 6 years between 1979 and 1985 and we assumed a stable exposure of tritium over this 6-year time period. Drs. Vakil and Harvey mistakenly suggest that this cohort was only followed for 6 years when it was actually followed for 20 years (as was the rest of the cohort), which does sufficiently consider the long latency period between exposure to tritium and potential development of cancer.

Regarding Drs. Vakil and Harvey's concern about using north Oshawa as our control group: 1) we acknowledged that north Oshawa does have a lower average neighborhood income; however, we did adjust for neighborhood income in our regression analyses; 2) much of north Oshawa is more than 10 kilometres from Darlington Nuclear Generating Station and a much greater distance away from Pickering, which is why we deemed north Oshawa a reasonable comparison population.

Finally, our conclusions are directly relevant only for those Ontarians living in the vicinity of PNGS and no other NPP in Ontario. For interested readers, Lane et al[9] have since published a study examining cancer risk around three NPPs in Ontario (including Pickering) in relation to modelled radiation dose estimates.

We are sensitive to community concerns regarding cancer risks associated with nuclear power generation; this is what prompted us to initiate this study. It could be that public concern may only be eased with comprehensive, individual-level tritium dose measurements and 20 years of meticulous follow-up of a well-defined cohort. However, considering both the enormity of such an endeavour as well as the weight of existing evidence regarding hazards from normally operating nuclear power plants, public health researchers must suggest feasible and practical means to address community concerns. There are limitations to our approach and we believe we described and adequately acknowledged these. However, these limitations do not outweigh the strengths of this work: 1) tritium estimation based on actual emissions data rather than using distance-to-the-source, which has commonly been used as a proxy for tritium exposure; and 2) use of a cohort design with consideration of a sufficient latency period between tritium exposure and development of cancer. The preceding two points are methodological improvements over previous studies. We therefore stand by our conclusions that tritium estimates in Pickering were not significantly associated with increased risk of those cancer sites examined. In regression analyses where we explicitly considered the association of tritium estimates and development of cancer, there was no evidence suggesting tritium estimates were significantly associated with lung cancer or female breast cancer. We could not look at other cancer sites, as we did not have adequate sample sizes to do so. However, in person-years analysis, observed risk of all cancers, female breast, leukemia, lung and thyroid cancers in the Pickering cohort were not higher than expected, given rates of these cancers in Ontario's general population. We have explained above why the finding of higher cancer risk in females aged 6 to 19 years should be interpreted with caution.

Susitha Wanigaratne, Eric Holowaty, Hedy Jiang, Todd Norwood and Mary-Anne Pietrusiak

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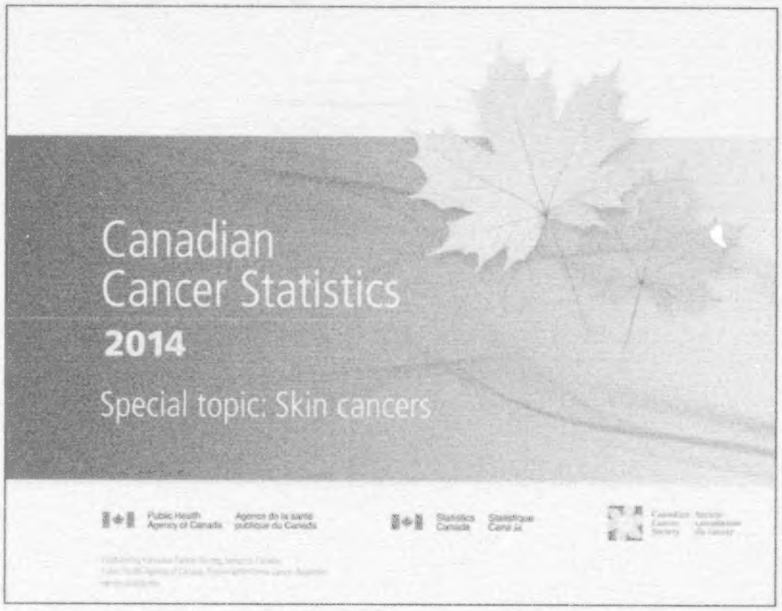

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